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Non-positive antiretroviral gay bodies

the production of sexual subjectivities in the realm of HIV prevention in England (1985-2020)

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The production of sexual subjectivities in the realm of HIV prevention in England (1985-2020)

by

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Abstract

Using a combination of oral history interviews and archival sources, this thesis analyses the role of antiretroviral drugs for HIV prevention in the lives of gay men in England. Through perspectives on biomedicalisation, governmentality studies and assemblage theory this thesis explores historical processes and philosophical questions regarding the production of sexual subjectivities related to HIV prevention. These processes include the increasing biomedicalisation of HIV prevention. Such biomedicalisation has produced the figure of the non-positive antiretroviral gay body, a concept that is used to frame the following aspects: (i) the question of agency of PrEP users in the context of what has been defined as a biomedical intervention, (ii) practices of freedom framed within neoliberal narratives of personal responsibility versus responsibilisation, and (iii) the governance of risk in the era of biomedicalisation. This thesis also looks at the role of different strands of public health in the implementation of PrEP in England and the role of PrEP activism, which is highly indebted to the activism of the 1980s and the first half of the 1990s, and the production of sites for collective action. Finally, this thesis uses the concept of prefigurative biopolitics as a way to ethically analyse how PrEP politics and activism have contributed or not to the values of egalitarianism and solidarity within the realm of HIV prevention. This thesis concludes that there is an historic opportunity for medicine and biomedical interventions to transform not only bodies and individuals but also societies. However, their success will depend on the democratisation of resources and the will to address inequalities and barriers to health with the same determination that has been present in producing new biomedical forms of care.

Table of Contents

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Chapter 1: Introduction

> In a way for me, PrEP is a miracle drug. Five years ago, if someone said, 'If we could invent this, would people want it?' I would be like, 'Who wouldn't want it?' We've not really seen it come into proper use yet, but still, ultimately, how to access it, the barriers in the way, are there. People are ashamed and reluctant and, 'What does this say about me? What more does this say about me?' kind of thing. (Leo. Age 40. Northeast London)

> Chemoprophylaxis may be a prevention strategy for the sexual transmission of human immunodeficiency virus (HIV). Evidence suggests that condom use has waned with the availability of antiretroviral medication, at least in some resource-rich settings. Barrier methods of HIV prevention have inherent problems, and the potential for failure. Microbicide research has focused primarily on male-to-female transmission. Analogous to post-exposure prophylaxis, HIV prevention may be achieved by preexposure prophylaxis in some settings. Research on this potential strategy may be rewarding (Mike Youle, MB, ChB;* and Mark A. Wainberg, PhD†, 2003)

Pre-exposure prophylaxis (PrEP) is a HIV prevention technology involving the self-administration of antiretroviral drugs. It represents a radical departure away from the use of antiretroviral medication to treat people who have already tested positive for HIV and towards a policy of prevention, targeting people identified at risk of contracting HIV. This thesis situates this shift in HIV prevention within the larger frame of the ongoing biomedicalisation of gay sexualities in England from 1985 to the present. The aim of the thesis is to explore the history of the processes of PrEP implementation in England in such a manner that serves as a case study to understand cultural practices and ethical values shaped by the relationship between gay men and the apparatuses of public health. For this purpose, this project makes a closer examination of the lived experience of gay men in relation to PrEP. It aims to understand the role of this biological intervention in shaping HIV-related identities. In this sense, this is

also a *lived history* project that takes into consideration the subjective experiences of PrEP users within the framework of biomedical intervention.

From these two visions of the project arises an interest in understanding the relationship between the gay population that self-regulates its sexual practices through PrEP and all those actors who make that self-regulation possible. This relationship is undoubtedly a power relationship in which biomedical knowledge and other types of discourse related to responsibility and the history of HIV prevention are inscribed on the bodies of those who use PrEP. But what kind of power makes this possible? Understanding this is a fundamental objective of this thesis and PrEP, again, serves as a window from which to observe how power relationships are articulated within a biomedical intervention.

With the previous aims in mind, I began to ask myself what kind of gay subjectivities could emerge from a process of public health intervention that was guided by actors in the HIV prevention realm. These PrEP-related subjectivities emerged from the interaction between public health agents delivering a biomedical intervention, on one hand, and gay men who engaged in such interventions, on the other. But what were the motivations for those who engaged in PrEP regimes? It is not difficult to understand the subjectivity of a person living with HIV who takes antiretroviral drugs. Without that medication, they would have little chance of surviving their condition. More complex and interesting, perhaps, are those HIV-free bodies in which antiretroviral drugs are present. They constitute an interesting case study for questions related to the governing of human bodies, as well as the agency and production of subjectivities related to this process of biomedical governmentality. Regardless of the fact that pharmacological development has managed to substantially reduce the level of toxicity of antiretroviral drugs, one would have imagined that the use of such drugs for prevention would find strong opposition among the gay population.

Arguably, since I began researching about PrEP, the interest in it, and number of gay men using it, in England has increased dramatically. Thus, in 2012, PrEP was only available in the UK for the 545 participants in the PROUD clinical trial, the first trial in England that aimed to measure the effectiveness of PrEP. The *56 Dean Street* sexual health clinic, part of Chelsea and Westminster Hospital NHS Foundation Trust, started privately prescribing PrEP and an indefinite, but quite limited, number of gay men were buying PrEP online. This number became larger by the end of 2015 with the creation of two websites that directed PrEP users to online pharmacies in other countries. By October 2017 there were an estimated ten thousand gay men buying PrEP. That same year, the PrEP IMPACT trial began the enrolment of another ten thousand gay men, and, by February 2020, at least twenty thousand gay men had been enrolled in the IMPACT trial and were using PrEP in England (NHS 2020). This indicates the impact that the use of antiretroviral drugs for prevention has had on the gay population in England, which has produced a number of questions that have guided this thesis.

One particular question that emerged was why would somebody whose body does not show antibodies for HIV, meaning they have not been infected by the HIV virus, engage in a regime of antiretroviral drugs? This question led to the following: What processes have facilitated thousands of HIV-negative gay men in England taking antiretroviral medication? What kind of gay men are subject to bio-governmental policies? What narratives underpin this phenomenon? What subjectivities arise from PrEP-related practices? How have these subjectivities been embraced by gay men in England? and, What are the implications of this intervention for the future of gay men in England in relation to the biomedicalization of sex?

In this thesis I propose the conceptual figure of *the non-positive antiretroviral gay body* as a starting point for researching the above-mentioned questions. This conceptual figure encompasses multiple subjectivities and it will help me to analyse different dimensions of PrEP; but perhaps the simplest way to disentangle this concept is to explain the reasons behind

the selection of each attribute of the concept: Why ‘gay’, why ‘body’, why ‘antiretroviral’ and why ‘non positive’ instead of the more common ‘HIV negative’?

Firstly, this project focuses on the experience of gay men, since they represent the latest embodiment of a historical process that has produced a number of sexual identities (Weeks 2016). Part of this historical process involves the medicalisation of sex between men, which has been subject to medical scrutiny since the nineteenth century. As a medicalised identity, the gay subject has been considered a passive and often oppressed subject. This is clearly the case for some men who underwent conversion therapy in England from 1935 to 1974 (Dickinson 2015). With the advent of the AIDS epidemic in the early 1980s, gay men came to play an active role in the prevention of HIV, which did not necessarily mean that they were freed from oppressive discourses. Within the frame of the AIDS/HIV epidemic, epidemiology made gay men the most prominent object of HIV prevention policies in England. The figure of the ‘gay man’ was repeatedly condemned morally when failing to adhere to official HIV prevention policies.

At this moment it is important to acknowledge the existence of the medical category MSM. MSM stands for ‘men who have sex with other men’ and is a category that emerged from HIV prevention discourses to include men who have sex with men but did not necessarily identify as gay. For example, there are men who identify as straight or heterosexual but nonetheless have sex with other men. These men do not participate in a common gay identity that often revolves around certain cultural practices and values. Therefore, although there is a large amount of HIV prevention literature on MSM, I decided not to focus on this category, since one of the main objectives of this thesis is to delve into the history of gay men and their relation with medicine through their connection with sex and antiretroviral medication for HIV prevention. However, I did pay attention to secondary data that included MSM literature, since it can provide a picture of the broader reach of the phenomenon of sex between men. Another

peculiarity of the gay identity in England is that it places its origins in a history of resistance and struggle for liberation and for sexual freedom and rights. The concept of non-positive antiretroviral gay body can be deployed to assert in which ways this subjectivity is inheritor of the gay origins. At the same time, there is also a history of assimilation of gay identities in normative structures through governmentality practices such as gay marriage, participation in the pink economy or pharmaco-regulatory practices, that will be useful for the analysis of the non-positive antiretroviral gay body. The analysis of this tension between these assimilationist practices in contraposition to the origins of resistance and the struggle for sexual liberation is important in this project. The question is the following: is the non-positive antiretroviral gay body a liberated body or an oppressed body subject to the mandates of the pharmaceutical industry and health authorities? This study will show that the answer to this question is more nuanced than this binary opposition implies.

Second, it is important to explain the centrality of the body to the analysis in the thesis. From the beginning of the HIV epidemic, gay bodies have been the loci for HIV- related interventions, including not only biomedical interventions, but also epidemiological interventions, as well as being the target of sensationalist mass media campaigns. In this regard, and as Petersen and Lupton have argued, ‘gay men's bodies have historically been subject to intense medical surveillance, as “deviant”, feminised and pathological—particularly in the wake of the AIDS epidemic—heterosexual masculine bodies have rarely occasioned such scrutiny’ (1996:85). Research on how and why various antiretroviral treatments take place in bodies is key to understanding changes in the social significance of the body. In this sense, as much as sites for intervention, bodies are also a site for resistance. Moreover, and as will be explored later, the body constitutes the site wherein historic, social and medical discourses are articulated, offering a tool for the analysis of such discursive practices and their effects on the

body. Thus, this thesis is a clear contribution to the field of 'body studies' that has expanded markedly since the 1980s (Shilling 2016).

Thirdly, by highlighting the term 'antiretroviral', the concept of the 'non-positive antiretroviral gay body' embraces a pharmaco-sexual subjectivity. I draw on the concept of toxic-pornographic subjectivities (Preciado 2013:35) to argue that the non-positive antiretroviral gay body is governed by the antiretroviral drugs that it consumes. This body is also the object of a certain pharmaceuticalisation of HIV prevention. Moreover, how gay men perceive the relationship with antiretroviral drugs shapes their views on responsibility, risk and other aspects related to their sexual citizenship. It is through antiretroviral drugs that gay men participate in new forms of sexual citizenship and create different meanings for their sexual experiences.

Lastly, I have made the decision to use the term 'non-positive' instead of 'HIV negative', which is the more common scientific term, in order to stress the idea that these bodies do not live with HIV but are still objects of potential life-long medicalisation. After all, the use of antiretroviral drugs is reoriented not to act upon the processes of morbidity associated with HIV's progress in the body, but rather to act as a preventive measure, focusing on preserving virus-free the bodies of those who take the drugs. This term resonates with a similar concept used on gay dating apps in which some men refer to themselves as 'negative on PrEP'. However, 'negative on PrEP' is a limited concept when addressing the multidimensional phenomenon which represents gay men taking PrEP.

In concluding this section, I note that throughout this thesis I refer to the term 'PrEP practices' to reflect on sets of practices that include not only the self-administration of the drug, but also the social and medical aspects of taking PrEP. The latter include, but are not limited to, the following practices: sex on PrEP, buying PrEP on the internet, PrEP-related peer education, PrEP-related activism and all those actions that are part of the processes of

implementation of PrEP in England. All these practices entail two governmental dimensions: on one hand, those related to the self-administration of PrEP and its impact on the body, and, on the other hand, those aspects characterised by exterior relations. The latter include the relations that gay men have with all the actors and organisations involved in the implementation of PrEP, as well as the activities derived from the government's action, or lack of it.

The following section provides a historical background to the dynamics between the government and the gay population in relation to HIV prevention and the AIDS epidemic. Some of the power dynamics that characterise the implementation of PrEP in England resemble interactions during the AIDS epidemic. This background also points to the moment in which the precedent for the non-positive antiretroviral gay body can be located. This moment is part of a longer history of the medicalization of gay men's sex, in which, however, sexual politics became confronted with normative values.

Historical background

The aim of this section is to outline the idea that sex between men has been significantly medicalised since the late nineteenth century – when sexologists began to show interest in studying and 'curing' homosexuality – up to our days of HIV research and the advent of PrEP. Thus, in the history of medicine, the sexuality of men who have sex with men became an example of medicalization in 1864, after physician K. M. Benkert coined the term *homosexuality* to define this conduct as a sexual behaviour disorder. It has been argued that 'in the face of movements toward increased prosecutions and arrest in late 19th century England and America, medical definitions of homosexuality offered a particularly viable intellectual alternative' to the legal harassment of men who had sex with men (Conrad and Schneider 1992:182). In this way, the medical categorization of homosexuality placed under clinical surveillance the sexual conduct of men who had sex with men, thereby treating sexual behaviour as an object of clinical treatment. The medicalization of homosexuality continued

during the twentieth and twenty-first centuries with varying intensity depending on geopolitical contexts. As stated by Conrad: 'The final piece necessary for the medicalisation of homosexuality was its inclusion in the American Psychiatric Association's official classification of psychiatric disorders, the Diagnostic and Statistical Manual of Mental Disorders, and its parent document, the World Health Organization's International Classification of Diseases' (Conrad 2007:99). In England, treatments to 'reverse' homosexual men into heterosexuals peaked during the 1960s and early 1970s and continued into the 1980s (Dickinson et al. 2012; Dickinson 2015). The declassification of homosexuality as a disorder came only in 1990 (Drescher 2015); but, by then, the HIV/AIDS epidemic had brought the medicalization of homosexuality into a new phase.

Since the 1980s, research on gay men's sexualities has been driven by the need to fight HIV and other sexually transmitted infections. This medical endeavour carried important consequences for thinking about gay sex, because the widespread association of HIV/AIDS with gay men meant that often the concept of sex itself was confused with disease. 'Being sexual' thus meant being 'treated as an illness or as evidence of illness' (Gagnon 1988:600). This medical understanding of gay sex along with public health campaigns informed the sexual experiences of gay men in England to the point that it is not unreasonable to state that gay sex is *medicalised* sex, and that HIV prevention strategies, both behavioural and biomedical, constitute one of the most important loci for the medicalization of gay sexualities.

The AIDS epidemic and the government response in England

The rise of the AIDS epidemic in England coincided with Thatcherite changes to the National Health Service (NHS) and the adoption of neoliberal policies in the 1980s, but in the context of the AIDS epidemic, it is not clear that the government took a solely managerial approach to the mitigation of the epidemic, at least in its early years. Responses to the AIDS epidemic were

different at different moments of the epidemic:

> AIDS illuminated the nature of power in the British state, but the way in which power was exercised was a dynamic and not a static process. The crisis of AIDS did underline some traditional modes of policymaking, but also drew on outsiders, both in terms of gay groups and the clinical specialties (Berridge 1996:6)

Thus, 1981 to 1984, the very first years of the crisis, were defined by an educated self-help response led by gay activists such as Tony Whitehead, who was the first chair of the Terrence Higgins Trust, and later worked in alliance with medical professionals. The alliance between activists and clinicians would be replicated in the future and became a key factor in the implementation of PrEP in England in the early twenty-first century. This early alliance was also due to the lack of response from the British government (Berridge 1996:21), since AIDS was perceived mainly as a gay issue that affected a very limited section of the population.

In fact, it was not until November 1986 that a full debate addressed the AIDS epidemic in the House of Commons. Norman Fowler, Secretary of State for Health and Social Services, stated: 'What make AIDS a serious threat is, first, the disease itself is believed to be invariably fatal. There is no cure, nor any immediate prospect of one. So, it is a deadly threat, and already in this country there have been 565 cases of which 284 have died' (HC Deb, 21 November1986, c799).[1] These were not high numbers in comparison to the number of victims in other parts of Europe, such as Spain or Switzerland. However, the mass media propelled a moral panic that part of the government in England embraced, producing a binary moral categorization between innocent victims and guilty victims (Hallsor 2017).

[1] https://api.parliament.uk/historic-hansard/commons/1986/nov/21/acquired-immune-deficiency-syndrome

Thus, from 1985 to 1986, during the moral panic about AIDS propelled by the mass media, the government conducted what has been defined as a liberal response (Berridge 1996). This liberal response was opposed to the punitive approach to the management of the crisis proposed by the conservative media, including compulsory testing, quarantine, abstinence, or drug use prohibition. The response to the AIDS crisis brought out the contradiction in which the New Right was mired: a defence of individual rights, confidentiality, safe sex, harm minimisation for drugs – a stance at variance with its public image of 'New Right reaction' (Berridge 1996) and its emphasis on traditional family values. The role of the Expert Advisory Group on AIDS (EAGA), which was set by the Chief Medical Officer Donald Acheson, was fundamental in defining this liberal response. The arrival of Acheson, who was appointed by Thatcher, symbolised the prime minister's 'determination to undermine the power of established bureaucracies' (Berridge 1996:67). But the EAGA, which was formed only by scientists and lacked representation from [the] gay groups, was able to force the government to create the first public education campaign on sexual health since Second World War (Ibid., p.96).

The campaign's slogan was 'AIDS: Don't Die of Ignorance'. The government's plan included the distribution of a leaflet to every household in the country containing ten information points about AIDS. Among those points the government warned that 'There is no cure. And it kills. By the time you read this, probably 300 people will have died in this country. It is believed that a further 30,000 carry the virus.' The leaflet did not include specific information for the gay population: however, it remarked that 'Any man or woman can get this virus depending on their behaviour. It is not just a homosexual disease'. This was a non-discriminatory public health campaign. In this sense the gay population was not targeted as irresponsible. However, a large part of the media did lay the blame on gay men. Following the delivery of the leaflet, the nation could view in their homes a striking television advertisement

featuring an iceberg and a tombstone to promote the idea that AIDS was a greater danger than people might have thought it was. This strategy was decided by a small committee including Sammi Harary, an advertising man whose strategy was to shock and alarm, Norman Fowler, who was more prone to send a message of urgency without creating panic, and four other civil servants (Berridge 1996). Thus, mass media and government cooperation brought the AIDS epidemic to a different level. In the words of the historian Matt Cook 'if the popular press sensationalised and shocked public opinion, government also incited fears and horror' (Cook 2017:55).

But, in reality, gay men in England negotiated this response in heterogeneous and very personal ways. The self-educated response and the media had a greater impact on people's sexual behaviour than any government action, but again the ways in which gay men reacted to the epidemic were not monolithic; neither were they always dictated by governmental policies. The National Lesbian and Gay Survey provides testimonies of gay men, who, at the time, had very different reactions to the epidemic. The following testimonies date from 1985:

> I am fully aware of the dangers of AIDS and am extremely cautious about having sexual contact with anyone. This has come at a time when I was beginning to find fulfilment in sexual expression and has had the effect of inhibiting my sexual activity.
> (NLGS respondent 250. Born in 1958 in York and living in London .27 years old).

> Naturally I am concerned over the AIDS question. I deplore the media rubbish such as published (sic) by the SUN as I find it so anti-gay that it is utterly indefensible. Regrettably some seem to believe it. Yes, AIDS does scare me, but I have not allowed it to infringe my lifestyle. At 49 I guess that I can afford to be more relaxed about it than the younger gays. I certainly do not have so much to lose. I am conversant with the safe sex guidelines but admit that I don't always follow them. I still enjoy fisting and carry on as before.

(NLGS respondent 278. Born in 1936 in Somerset living in Newcastle upon Tyne. 49 years old).

> Government is not doing enough, and it probably never will. If government is unwilling to do enough about poor housing, famine, unemployment, the redistribution of wealth and pollution it is hardly likely to spend much time and money in educating the public about AIDS, which I suspect is not viewed by the government as a threat to more than a small part of the population. Whatever the rights or wrongs about these priorities, this position of Government seems to be fact. So, who is there left to do anything about AIDS? Us. The buck stops with us. […] With my 'head' I know and understand safe sex. In the (e)motion and intensity of intimacy, this knowledge does not always work, and I suspect we are all likely to engage in riskier sex for the sake of a greater and better orgasm.
> (NLGS respondent 234. Born in 1952 in Bradford living in Cumbria. 33 years old).

From almost giving up sexual practices with other gay men to engaging in practices deemed higher risk/unsafe these testimonies suggest that regardless of the government's actions or inactions, gay men's subjective sexual experiences in the face of an AIDS epidemic were complex and diverse. As happens with most government guidelines, these were subject to varying responses, from to total take up, to scepticism, total rejection or plain ignorance. This same complexity and heterogeneity will be key to understanding the experience of the non-positive antiretroviral gay body. Nevertheless, the government's 1985 liberal response constituted a precedent for the representational practices of the non-positive antiretroviral gay body in the future. These practices are a combination of a non-moralistic and sex positive mentality in the realm of HIV prevention, along with new forms of self-understanding derived from the gradual dissemination of neoliberal ideologies related to the care of the self and discourses on personal responsibility. Liberalism, both ideological and economic, is key to understanding the emergence of the non-positive antiretroviral gay body, part of a subject who takes personal responsibility for his own sexual health, and whose sexual practices are framed

in opposition to previous safe sex recommendations for HIV prevention. The next section of this introduction points to the development of chemical prophylaxis as key site for the biomedicalisation of HIV prevention practices in England.

The origins of Pre-Exposure Prophylaxis

The use of drugs for prevention purposes, rather than the of treatment of disease, is not a new phenomenon. This practice, called *chemoprevention*, requires the self-administration of 'pharmaceuticals or nutraceuticals to prevent disease' (Fosket 2010:331). The birth control pill, introduced on the market in the United Kingdom in the 1960s, marked the first time in which one part of the population — heterosexually active women of child-bearing age — was targeted for daily doses of pharmaceuticals. Chemoprevention has also been a part of heart disease prevention since the 1960s (Shim 2002; Fosket 2010). Thus, the first clinical trials using beta blockers such as Propranolol date from that decade (Hebb et al. 1968) and since then Propanol has been used to prevent angina, heart failure or high blood pressure. Other areas of chemoprevention include diabetes, prostate cancer, asthma, bone disease, and fractures, as is the case of Tamoxifen for women at high risk of breast cancer (Nazarali and Narod 2014). In the case of cancer, the 1980s saw an increased interest in chemoprevention via nutraceuticals that continues to the present day (Fosket 2010). Therefore, by the time the human immunodeficiency virus was first identified as the cause of AIDS in 1983, chemoprevention was an established preventative treatment method.

In the early years of the AIDS epidemic, the search for a cure focused on the investigation and development of antiretroviral drugs; AZT was the first of these to be tested

in 1984.[2] The use of antiretroviral drugs as a preventative intervention has a clear antecedent in the attempts to reduce and avoid vertical HIV transmission from mothers to neonatal children. A paediatric clinical trial conducted from 1991 to 1993 concluded that a regimen consisting of giving AZT 'ante partum and intra partum to the mother and the new-born for six weeks reduced the risk of maternal-infant HIV transmission by approximately two thirds' (Connor et al. 1994:1173). However, AZT by itself proved not to be an effective drug either for reducing mortality or improving quality of life. This was demonstrated in a clinical trial named Concorde that involved 1749 HIV positive individuals from medical centres in the UK, Ireland, and France (Concorde Coordinating Committee 1994:871). The protocol for the trial was designed by the British Medical Research Council and its equivalent body in France and ran between 1988 and 1991. It took more than ten years for the scientific community to begin to speculate on the possibility of using antiretroviral drugs as an HIV prevention strategy.

Before effective antiretroviral treatment, HIV and AIDS prevention strategies were mainly focused on behaviour, meaning that prevention was aimed at modifying the sexual conduct of gay men via condom use, serosorting (choosing sexual partners according to their HIV status), seropositioning (practising receptive or insertive anal sex according to the partner's HIV status) or (serial) monogamy (Giami and Perrey 2012; Russell 2005). These were strategies that individuals could take to protect themselves. From a public health perspective, testing as a biomedical tool was also encouraged. However, numerous testimonies from this study, and from my own archival research, point out that many gay men did not want to know their HIV status, since there was little to no medical treatment available before the advent of antiretroviral medication. With the passing of time and techno-scientific advances,

[2] Zidovudine (ZDV), also known as azidothymidine (AZT), was first synthesized in 1964 with the aim of treating cancer under the belief that some types of cancers were caused by environmental retroviruses.

as well as pharmacological development, HIV prevention strategies have become more focused on biomedical and pharmaceutical strategies. This is, in part, because according to clinicians, the use of medication is assumed to be much easier than changing behavioural patterns altogether (Grant et al. 2010). This process is part of the biomedicalization of HIV prevention, that includes medical strategies such as 'mass testing, drugs and pharmaceutical products for chemoprevention and treatment, as well as the surgical technique of male circumcision' (Giami and Perrey 2012:353).

In 2003, Mike Youle and Mark Wainberg, noticing that antiretroviral drugs had begun to become effective at the same time that records showed a decline in condom use among gay men in the US, suggested for the first time that chemical prophylaxis could work as a prevention strategy for the sexual transmission of HIV (Youle and Wainberg 2003). They also suggested that a combination strategy, namely condom use plus the use of antiretroviral drugs for prevention, would have more chances of success. Moreover, they made a point that would become a constant theme in the future debates of Pre-Exposure Prophylaxis, especially in England: cost-effectiveness. Cost-effectiveness had already been addressed when using antiretroviral drugs after exposure to the virus (post-exposure prophylaxis or PEP), in which a relatively short period of treatment with antiretroviral drugs was estimated to cost less than a life-treatment cycle (Pinkerton et al. 1998). PrEP was designed as a preventive treatment consisting of the self-administration of a daily pill containing a fixed-dose combination of two antiretroviral drugs: *tenofovir disoproxil fumarate* (TDF) 300 mg and *emtricitabine* (FTC) 200 mg. The treatment required quarterly screenings to rule out HIV infection as well as liver and renal insufficiencies. This treatment involved fewer drugs than the previous combinations of Anti-Retroviral Treatments (ART) prescribed for HIV treatment.

The year 2004 saw the beginning of the design of the protocol for an international clinical trial involving eleven study sites — Brazil, Ecuador, Peru, Thailand, South Africa, and

the United States (Grant et al. 2010). The study, called *iPrEx*, which derives from the Spanish *Iniciativa Profilaxis Preexposicion* (Pre-Exposure Prophylaxis Initiative), was a randomised controlled trial funded by the National Institutes of Health and the Bill and Melinda Gates Foundation. It enrolled 2,499 men who had sex with men and transgender women who had sex with men. As in all randomised controlled trials, participants were allocated either the treatment to be tested (in this case PrEP), or a placebo as a control mechanism. For the iPrEX study, one group of trial participants received a combination of 200 mg *emtricitabine* and 300 mg *tenofovir disoproxil fumarate* in a single pill (Truvada), while the second group was given a placebo pill. Results of the study were published in December 2010 in *The New England Journal of Medicine*, and concluded, 'Oral FTC- TDF provided protection against the acquisition of HIV infection among the subjects. Detectable blood levels strongly correlated with the prophylactic effect' (Grant et al. 2010:2587). The US Food and Drug Administration, which subsequently approved the use of Truvada for Pre-Exposure Prophylaxis in 2012, welcomed these results.

In 2012, the clinical trial known as the PROUD study (Pre-exposure Option for reducing HIV in the UK: an open-label randomisation to immediate or deferred daily Truvada for HIV negative gay men), opened the gates for the debate on antiretroviral drugs for HIV prevention in England. Recruitment for participants took place in thirteen different sexual health clinics, including London (eight sites), Brighton, Birmingham, York, Manchester, and Sheffield. Sheena McCormack, Professor of Clinical Epidemiology, and David T. Dunn, Professor of Medical Statistics, both at the MRC Clinical Trial Unit at University College London, led the study. Its purpose was to assess the effectiveness of PrEP in a real-life scenario. In contrast to other PrEP blind trials conducted elsewhere in the world, the PROUD study was an open label trial, meaning that both the researchers and participants knew which treatment was being administered and that, most importantly, there were no

participants receiving placebo doses. While prior trials had confirmed the effectiveness of PrEP in reducing HIV transmission, the PROUD study aimed to assess whether the participants would engage in riskier sexual activities because of feeling more protected by the antiretroviral drugs.

On February 24, 2015, McCormack released the results of the PROUD study at the Conference on Retroviruses and Opportunistic Infections (CROI) in Seattle. The authors concluded that the combination of the antiretroviral drugs *Tenofovir/Emtricitabine* 'conferred impressive protection against HIV, and higher than the levels previously observed in the placebo-controlled trials. Concerns that effectiveness would be undermined in a real-world setting were unfounded' (McCormack and Dunn 2015:89). However, it is necessary to clarify that the question of whether participants engaged in riskier activities, namely using condoms less often than before, or having a larger number of partners, was not answered by the study. This is because the authors used the number of sexually transmitted infections as an indicator to show that participants did not engage in riskier behaviour. The published data focused on the number of HIV infections that occurred within the trial. But as their own subsequent article states, the lack of data on sexual behaviour was a limitation (McCormack et al. 2016). However, the same study reports that participants used condoms less often over time: 'a larger proportion of participants allocated to immediate PrEP than allocated to deferred PrEP reported receptive anal sex with ten or more partners without a condom (21% vs 12%)' (Ibid., p.8). Despite this change in behaviour, the efficacy of PrEP in preventing HIV was not affected.

Nevertheless, the PROUD data, welcomed by HIV organizations around the world, became the basis for future demands for PrEP implementation in England. As will be thoroughly explained in chapter three, this demand led to a struggle between the NHS and activists who wanted PrEP to be accessible to all those who needed it. The question of who needed PrEP was shaped by the concept of risk and was resolved in epidemiological terms.

Thus, key populations with higher incidence of HIV infection, of which gay men were above any other population, were targeted as the main beneficiaries of this biomedical intervention. This targeting constituted a new chapter in the (bio)medicalisation of gay sex in England, especially regarding the aspects of HIV prevention. Although not without precedent, the biomedicalisation of HIV prevention for gay men in England has reached its maximum height. Thus, along with different regimens of PrEP, HIV prevention tools include treatment as prevention (TasP), post exposure prophylaxis (PEP) and different HIV testing options. Not only that, a visit to the sexual clinic in the next year can include vaccination for hepatitis B and human papillomavirus.

There are two recommended regimes for PrEP use, depending on the subject's level of sexual activity and on their ability to know when condomless sex is going to happen. The first regime is based on the self-administration of a daily pill containing a fixed-dose combination of tenofovir disoproxil fumarate (TDF) and emtricitabine (FTC). The second regime is called 'on demand' and requires the person to take two pills twenty-four hours before sex, one pill one day later and another pill the day after that. Truvada is the branded name and most well-known version of the tablet among other existing branded and generic forms. But taking the tablet is only a part of this prevention technology. Guidelines on PrEP recommend a quarterly test for other sexually transmitted infections and an annual test for kidney monitoring (BHIVA 2018). Thus, although it is common to hear or read phrases such as 'buying PrEP', or 'being on PrEP', this language is an accepted 'reverse' synecdoche, which uses the whole (PrEP) to refer to a part (the antiretroviral drugs). This troubled use of the word PrEP probably originated for the sake of simplifying information. PrEP also needs to be differentiated from post exposure prophylaxis (PEP), which is also classified as a prevention treatment that can be taken after being exposed to a possible infection. The drugs contained in PEP include those in PrEP, plus

either raltegravir or dolutegravir, and PEP needs to be taken within four weeks of exposure. As will be mentioned later in the thesis, PEP can be regarded as the precursor of PrEP.

Chapter breakdown

In this chapter, I have introduced the phenomena of the use of antiretroviral drugs within the historical context of the HIV / AIDS epidemic in England. I have demonstrated that, from the nineteenth century onwards, the medicalisation of sex between men is a historical continuum that peaks with the advent of PrEP in the twenty-first century. This medicalisation of sexual behaviours has undergone a profound transformation since its origins, and now it has become necessary to understand what the role of medicine is in the lives of those men who have sex with other men. Thus, with the shift towards biomedicalization, new forms of everyday politics and practices have emerged, as well as transformations in individuals' understandings of themselves and their lives (Clark et al.2003; Rose 2007a). As has been explained, this thesis uses PrEP as a window from which to contemplate changes in social and cultural values within the gay population.

Chapter 2 describes the theoretical framework in which this thesis is developed, as well as the methods for data collection and analysis. The theoretical framework of this thesis has its foundations in three main social theories, namely: assemblage theory, governmentality and biomedicalization. I deploy assemblage theory to frame all the actors that are part of the PrEP implementation process in England. The concept of governmentality, in addition to being used as a theory of power based on networks or assemblages, offers a type of methodology that allows for the analysis of the dynamics between the actors of such networks or assemblages. In addition, it offers the means to analyse the ethical government of the self. The third social theory talks about those processes that have made possible the intensification of medicalization in everyday life, including taking PrEP. The joint use of these three social theories provides a

larger perspective that hints at the complexity of the PrEP phenomenon in England. This chapter concludes with an explanation of the methods used for this thesis, including oral history interviews, archival research and secondary research. For the sake of the ethics and credibility of the thesis, I have included a section on my positionality in this research, commenting on my past as an activist and my historical relationship with HIV issues.

Chapter 3 focuses on how PrEP users are experiencing some of the processes described in biomedicalisation theory. The advent of PrEP has led to a wave of (bio)medicalisation affecting 'non-positive' bodies that differs significantly from previous episodes of gay medicalisation in the history of England. This wave of biomedicalisation features a diversification of sources and distribution of HIV knowledge that includes expert lay knowledge, new forms of self-understanding in relation to HIV and sex politics, and a certain pharmaceuticalisation of sexual risk, a process that in England includes DIY PrEP users buying generic Truvada online without prescription. Thus, this chapter will focus on describing the process of commodification of HIV prevention in England through an historical overview of the ongoing privatisation of the NHS and then through the testimonies of the participants who bought PrEP online. The chapter continues by arguing that the commodification of PrEP reveals that gay men in England, far from being traditional objects of medicalization, are active subjects of self-biomedicalisation; it will look at how gay men in England are producing forms of self-understanding in relation to HIV prevention and the sourcing of PrEP. The chapter will discuss some theoretical approaches to the transformation of bodies and techno-scientific identities while supporting them with testimonies of PrEP users. The chapter concludes that PrEP users in England are choosing, for legitimate but not always medical reasons, to engage in biomedical HIV prevention. Thus, fears, pleasures, sexual desires and moral values are becoming human factors co-constitutive of biomedicalisation practices, with as much weight as science, in the PrEP-related decision-making process of gay men in England.

Chapter 4 argues that the "PrEP response" emerges from the succession of three different ideological lines of public health promotion in England, along with new forms of commodity activism, resulting in a historical decrease in HIV infections in England, but also in a new degree of commodification of HIV prevention. Thus, in the first place PrEP activism echoes what has been defined as a 'new lifestyle-oriented, activist single-issue public health' that thrived in the 1970s (Berridge 2007:2). This decade witnessed the collaboration of the government and health activists to the point that it was possible to talk of a 'state-funded activism' (Ibid., p.16). Secondly, PrEP activism is the successor to an environmentalist public health model that emerged in the 1980s and gave rise to the 'environmentalist citizen', described as a 'rational consumer, one who engages as an autonomous individual in activities to prevent or reduce environmental damage and to protect herself or himself from health risks believed to be generated by the environment' (Petersen and Lupton 1996:90). And finally, PrEP activism aligns with pharmaceutical public health, a type of public health that emerged in the 1990s and that saw in drugs and vaccination a solution to public health issues, along with a new frame in the relationships of the state with the pharmaceutical industry (Berridge 2007). These three a priori, unrelated public health models converge in PrEP activism, which brings to the forefront internet marketing strategies. While this convergence might suggest the influence of a neoliberal ideology, this type of activism has also engendered a form of collective agency based on a pharmaceutical/antiretroviral care of the other ethos that needs to be better understood in the light of future biomedical interventions.

Chapter 5 aims to examine the PrEP subject in relation to neoliberalism while exploring the problem of constructing the PrEP user in England as a neoliberal sexual actor. During the last 15 years there has been a debate around the gay sexual actor that embodies neoliberal values of personal responsibility, market choice, rational risk analysis and personal entrepreneurship (Sandet 2019; Martinez-Lacabe 2018; Thomann 2018; Adam 2005, 2006;

Adam and Rangel 2016). This chapter sheds light on this problematic conceptualization of PrEP users as neoliberal sexual actors in England.

Chapter 6 is titled 'PrEP practices: practices of government and practices of freedom within a HIV prevention intervention'. The chapter draws on Foucauldian notion of power to reflect on the reasons that gay men in England choose to use PrEP. Condomless sex, control of fear and the ability to choose are themes that emerge in the interviews as liberating practices in the field of HIV prevention. The chapter interrogates the authenticity of the subjective experience of freedom within the rhetoric of risk in HIV prevention. Furthermore, it explores how PrEP practices engender a zero-risk narrative that may contribute to the stigmatization of gay men who do not engage in PrEP practices while at the same time contributing to a reconfiguration of HIV-related communities.

Chapter 7 reflects on the concept of prefigurative politics with the aim of analysing the ways in which the PrEP response in England reflects democratic, solidary and community-values. With this aim in mind, I will deploy prefigurative politics as an ethical framework to analyse some aspects of the PrEP response in England. Prefigurative politics is a term of anarchist origins, widespread in various activist movements, described as the modes of organization and tactics performed that accurately reflect the future of the sought society. I draw on this concept to raise the question of to what degree PrEP activism strategies in England reflect the envisioned future by the HIV activist assemblage.

Chapter 8 (Conclusion) summarises the key findings of this study according to three areas of contribution: the theoretical, the methodological, and the empirical – along with reflections on directions for future research that conclude the thesis.

Chapter 2: Theoretical foundations and methodological approaches

This thesis draws much of its analytical framework from the work of Michel Foucault, especially that related to the intersections of moral subjectivity and sexuality, as well as the practical applications of biopower through governmentality practices. It also benefits from the work of the History of the Present Research Network, funded in 1989 by Nikolas Rose, that continued Foucault's work and further developed some of his theoretical concepts. From this network, I largely take inspiration on Mitchell Dean's work on governmentality (1999) to analyse the forms of government in the realm of the gay male. Thus, this chapter delves into three social theories that have shaped the analysis of this thesis. I use these three theories – namely, assemblage theory, governmentality and biomedicalisation – with the following aims in mind: (i) to locate the roots of governmental agents and actors within the process of implementation of PrEP in England; (ii) as an analysis of government; and (iii) as a way to frame the intervention in processes related to the intensification of the role of medicine in gay men's lives. The latter part of the chapter looks specifically at the methods deployed to obtain primary data as well as including a reflexivity section that provides information about my positionality in this research.

I first introduce Manuel DeLanda's synthesis of assemblage theory (2016) to develop the concept of the HIV assemblage in England. Assemblage theory applied to the HIV prevention realm facilitates the theoretical underpinning of the emergence of the non-positive antiretroviral gay body. Moreover, assemblage theory provides a theoretical perspective by helping to locate the interactions involved in the history of PrEP as a biomedical intervention in England.

Next, I describe how the concept of governmentality can be applied to the gay population, specifically within PrEP practices. First, I explain what the concept of

governmentality is and how it relates to practices of exteriority, that is, all those aspects that have to do with the distribution of power and its actions upon the gay population in the field of HIV prevention and PrEP. Second, based on the work of Mitchell Dean, I explain how to analyse the government of the self from an ethical point of view. This includes basic questions of how, why, and for what purpose antitretroviral drugs are taken.

The theoretical section focusses then on the critical framework in which gay governmentality practices in relation to PrEP occur. This critical framework is the historical turn from the medicalization to the biomedicalization of gay sexual practices. In order to describe that framework, I consider first how the concept of medicalization is interpreted differently by different social theorists. The section continues by describing the turn to biomedicalization and ends by defining the processes that constitute this phenomenon to conclude that PrEP practices connect with each one of those processes.

Theorising the HIV/AIDS assemblage in England

Assemblage theory is a realist approach to social ontology that, as with any ontology, is 'concerned with the question of what kind of entities we can legitimately commit ourselves to assert to exist' (DeLanda 2006:1). As explained by Rosengarten and Michel 'PrEP and HIV prevention' can be understood 'as an assemblage that is ontologically open rather than, as more usually conceived, made of stable and distinct objects: drugs, bodies, condoms and virus' (2010:167). In fact, assemblage theory places its focus on the processes of assembly of different social entities, including persons, networks, organizations, governments, cities and nation-states. All these entities can be considered assemblages constructed 'through very specific historical processes, in which language plays an important but not a constitutive role' (Ibid., p.4). Manuel DeLanda synthesised the theory by drawing on Gilles Deleuze and Felix Guattari's *A Thousand Plateaus* (1988), concluding that an entity which is classified as an assemblage must fit within certain constraints. Firstly, the whole of the assemblage can't be

reduced to one of its parts. For example, we cannot reduce the HIV assemblage to one person, one network, or one organization that is part of the assemblage. Second, an assemblage is not a totality in which its components are fused. The constituents in an assemblage maintain their autonomy and can be detached from one assemblage to be placed in other assemblages. A PrEP activist, for example, can take part in other assemblages. This point determines a crucial concept within assemblage theory: relations of exteriority. In contrast to relations of interiority in which the parts of a whole cease to exist outside the whole (since the whole is part of their constitution), the parts in assemblages have complete autonomy (DeLanda 2006:9). Third, in an assemblage the parts need to interact to bring about emergent properties. From the interaction of the parts a new whole is created. Part of the goal of this thesis is to demonstrate that the emergence of new gay subjectivities occurs from the interaction of the parts in the HIV assemblage, an interaction that is governed by PrEP practices.

There are two parameters that define the conformation of an assemblage: (i) lines of territorialisation that will help to determine the grade of definition of an assemblage, and (ii) coding and decoding, in reference to the grade of deployment of codes that allows the territorialisation or deterritorialisation of an assemblage. Apart from these two parameters, Manuel DeLanda adds a third dimension in which it is possible to observe 'the variable roles which component parts may play, from a purely material role to a purely expressive one, as well as mixtures of the two' (Ibid., p.18). Territorialisation can be understood literally, so that an assemblage can be defined by its physical boundaries, as happens in the case of neighbourhoods or nation states. The clearer the boundaries are, the better defined the assemblage. Territorialisation can also be understood in non-spatial terms. In this sense, territorialisation would include all the processes that help to maintain or increase the homogeneity of the assemblage. A common goal such as reducing HIV infections could be an example that can build up a stronger territorialisation. On the other hand, all processes that

destabilise the homogeneity of the assemblage are processes of deterritorialisation (Ibid., p.14). As DeLanda shows, 'one and the same assemblage can have components working to stabilize its identity as well as components forcing it to change or even transform it into a different assemblage' (Ibid., p.12). This is related to the fact that assemblages are, as noted earlier, defined through expressive and material components. Different cultural backgrounds or ideals also work as an example of what can deterritorialise an assemblage. In the case of the HIV assemblage, it is necessary to clarify that its components are in turn assemblages composed by other assemblages whose composition varies in expressive and material components. Thus, the HIV activist assemblage might have fewer material components than the pharmaco-biotechnological companies concerned with HIV (an obvious example of this would be financial capital), although the latter probably entails less expressive material than HIV activist assemblages. The fact that assemblages can be defined through parameters makes it impossible to think about them as fixed identities; they are always subject to change.

To acknowledge the existence of the HIV assemblage is to acknowledge that there is a frame of technologies encompassing a system of mechanisms that work in different ways for a disparity of goals. This disparity of goals is due to the fact that the social entities involved in the HIV assemblage have identity properties of their own. In this sense, these entities don't need to collaborate with each other to be functional. Thus, a person in charge of the management of a PrEP clinical trial does not need to collaborate with, for example, a PrEP activist for the PrEP trial to be effective. In fact, the constituents of the assemblage often seem to work in different directions, but this happens because every entity is endowed with, and produces its own, technologies. By definition, technology refers to the application of scientific knowledge for practical purposes, so that if we talk about HIV as an agglutinant technology that produces gay governmentality (specifically through pharmaco-regulatory practices) it is essential to know who the knowledge production agents are, how they interact with the other

agents in the assemblage and with what purposes. Steve Epstein (1996) concurs that many diverse, ostensibly unconnected actors are responsible for HIV and AIDS knowledge production:

> Inside a large and often floodlit arena with a diffuse and porous perimeter, an eclectic assortment of actors has sought to assert and assess credible knowledge about AIDS: biomedical researchers and health care providers of different stripes; activists, advocacy groups, and people living with AIDS or HIV infection; health educators and social scientists; politicians and public health officials; government agencies and advisory committees; pharmaceutical and biotechnology companies; writers, journalists, and the institutions of the mainstream and alternative media. What we know about AIDS is the product of this elaborate, often heated, and in some ways quite peculiar complex of interactions. (Epstein 1996:2)

It is within this representation of actors in the HIV and AIDS assemblage that we need to look for the origins of HIV governmentality practices. In this location, the different knowledge producers interact and may conflict with one another, as the goals of these agents often differ. Thus, the pharmaceutical and biotechnology companies aim to produce new forms of HIV treatment that provide them with financial profits, such as the single tablet regime or less toxic treatment lines of antiretrovirals that help users to adhere to the drug regime. The work of today's HIV and PrEP activists largely focuses on speeding up the availability of drugs to those who need them. Government agencies might provide data that mainstream media release to the general public, contributing to perpetuating HIV-related stigma. Similarly, health educators may put a focus on key populations, stigmatizing specific groups at the social level. This positioning, which is motivated by the goals of the constituents of the HIV assemblage, reinforces the territorialisation of the sub-assemblages by highlighting the difference between *us* and *them* (DeLanda 2006:58), but it also contributes to processes of emergent subjectivities. These new subjectivities are the outcome of processes of emergence derived from complex

relations of exteriority embedded within the HIV assemblage. This ontological view allows us to frame the problem of subjectivity in a dimension that links the micro (the self-governing practices) with the macro (the processes of implementation of PrEP in England).

Applying the notion of governmentality to the realm of PrEP practices

Part of the focus of this thesis is on describing the power mechanisms that are involved in the history of PrEP as a biomedical intervention, as well as analysing which are the processes that enable the articulation of discursive practices in the bodies of the gay population. By discursive practices I refer to the Foucauldian notion that has to do with the production and distribution of expert knowledge and that has a profound effect on people's HIV prevention practices: 'Discursive practices are not purely and simply modes of manufacture of discourse. They take shape in technical ensembles, in institutions, in behavioral schemes, in types of transmission and dissemination, in pedagogical forms that both impose and maintain them' (Foucault 1994:12). This description of the production of discursive practices resonates with the mechanisms of knowledge production of the HIV/AIDS assemblage explained in the previous section. But what kind of phenomena allows the articulation of discursive practices on non-positive antiretroviral gay bodies?

In answering these questions, first it is necessary to acknowledge that although gay bodies in England have been the target of various biomedical interventions, this intervention must not be understood as a vertical downwards imposition. The presence of antiretrovirals in non-positive bodies indicates new forms of horizontal governance in the realm of HIV prevention. Thus, it would be more appropriate to speak in terms of an assemblage that acts upon gay men by promoting technologies of the self. Secondly, it is necessary to clarify the question of what mechanisms are involved within an intervention that features biopolitics at the molecular level. The concept of governmentality, that was largely articulated as a form of critique of the state power over population, can be used as a theoretical tool to analyse the

forms of power that the HIV/AIDS assemblage exercises both over the gay population and over gay bodies in England.

Governmentality has been defined as the 'the type of power that we can call "government,"' (Foucault 2007:108) which basically works through the 'conduct of the conduct' (Gordon 1991:2) and has mentality as a feature of power. Thus, the phrase 'the conduct of conduct' has been deployed as the epitome of the concept of government. The verb conduct means to lead, to guide. In a figurative use, it means 'to guide or direct in a certain course of action; to bring to a place, a particular condition or situation, a conclusion, etc' ('Conduct' 2017). It is a transitive verb, which means that the action of conducting requires: (i) a conducting subject and (ii) an object that is conducted, in this case, the *conduct*. The latter refers to behaviour. In this sense, conduct is often deployed to talk about children's behaviour in school, or the behaviour of people in the workplace.

The moral and ethical component clearly shows when the term *conduct* is deployed to express behaviour. Thus, we might say that people with a work ethic conduct themselves in a professional and responsible manner. As stated by Mitchell Dean, these discussions involve, on one hand, a set of rules, and on the other hand, the assumption that there are 'agents whose responsibility is here to ensure that regulation occurs, e.g. teachers or professional associations and their "codes of conduct"' (Dean 1999:10). It is safe to state that there is an indefinite number of aspects of human behaviour that can be changed, shaped and transformed by government practices. This thesis narrows its focus to the governance of those aspects related to sexual practices and HIV prevention within the gay population. As suggested by Dean before, to transform behaviour, it is necessary to have the presence of an indefinite number of regulatory agents. It is from this rationale that the following definition of government can be understood:

> Government is any more or less calculated and rational activity, undertaken by a multiplicity of authorities and agencies, employing a variety of techniques and forms of knowledge, that seeks to shape conduct by working through our desires, aspirations, interests and beliefs, for definite but shifting ends and with a diverse set of relatively unpredictable consequences, effects and outcomes (Ibid., p.11)

This thesis studies the governance of the gay population within the realm of HIV prevention, and for that it is necessary to pay attention to the multiplicity of authorities and agencies which, by deploying an array of techniques and forms of knowledge, shape and modify the behaviour of the gay population operating, as will be revealed by data provided in this thesis, through sexual desires, aspirations of not seroconverting, interests of being healthy subjects and through beliefs of community integrity. All these elements help to shape gay governmentalities in the HIV and AIDS realm and are part of the formation of sexual subjectivities. Although the above definition of government puts the stress on relations of exteriority and the dynamics of the governors and the governed, government practices also encompass forms of self-governance that will be addressed later. However, before delving into these self-regulatory processes, I will focus on how the Foucauldian critique of governmentality can be used to analyse the HIV/AIDS assemblage.

Governmentality and exteriority relationships

In his lectures on security, territory and population (1976), Michel Foucault refers to governmentality as a 'dark' and 'diffused' concept, nevertheless necessary to understand the power relationships between state institutions and the population. He proposed a triple definition that can be taken as a starting point for the discussion on governmentality:

> First, by "governmentality" I understand the ensemble formed by institutions, procedures, analyses and reflections, calculations, and tactics that allow the exercise of this very specific, albeit very complex, power that has the population

> as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument. Second, by "governmentality" I understand the tendency, the line of force, that for a long time, and throughout the West, has constantly led towards the pre-eminence over all other types of power – sovereignty, discipline, and so on – of the type of power that we can call "government" and which has led to the development of a series of specific governmental apparatuses (*appareils*) on the one hand, [and, on the other] to the development of a series of knowledges (*savoirs*). Finally, by "governmentality" I think we should understand the process, or rather, the result of the process by which the state of justice of the Middle Ages became the administrative state in the fifteenth and sixteenth centuries and was gradually "governmentalized" (Foucault 2007:108)

This triple definition points to the complexity of a phenomenon that locates population as the main focus of institutional strategies and tactics with a non-vertical application of power. It also states that such strategies that include the development of knowledges/expertise and knowledge-producer apparatuses are forms of government that have more predominance than other forms of power. In this sense, governmentality embodies a paradigm shift from *ruling* to *governing.* It is derived from the fact that 'far for preventing knowledge, power produces it' (Foucault 1980:59), in the form of scientific theories, biostatistics, etc. However, it should also be mentioned that contemporarily, there is a coexistence of both forms of power: the disciplinary and the strategic. Foucault also argued that beginning in the eighteenth century 'the social "body" ceased to be a simple juridical-political metaphor (like the one in the Leviathan) and became a biological reality and a field for medical intervention' (Foucault 1978:7).

Within the theoretical frame of this thesis, Foucault's definition of governmentality applies to the government of the gay population in England, not only because it is the target of certain institutions' strategies and tactics within the HIV and AIDS assemblage, but also because the gay population has been a historical body deeply affected by medicalization. Thus,

when conceived as a form of gay governmentality, PrEP related practices involve two levels of government. The first level is concerned with practices of self-governance and the self-administration of Truvada. The second level involves an external dimension that encompasses the targeting of a gay population as the population that benefits the most from the treatment, the involvement of a multiplicity of knowledge producer agents to promote the practice, and – finally – the attempts to implement PrEP.

Foucault explains that the concept of governmentality allows for a triple displacement in the analysis of the relations of power towards (i) the exterior of the institution, (ii) the function of the institution and (iii) the object of the institution. By drawing a parallel with this triple displacement, it is possible to have a broader perspective that can be used for the analysis of the dynamics of power occurring between the gay population in England within the HIV and AIDS assemblage. The first displacement consists in replacing what Foucault calls an 'institutional-centric approach' with an approach that allows an analysis of the institution set apart from the norms and the relations of interiority that characterise the institution, and that are normally used to assess the institution. Thus, what happens is a shift of focus from the inside of the institution to the externality of the power relations that happen around the institution. Foucault used the *hospital* as an example of an institution that can only be completely understood from outside (Foucault 2007:117). He claimed that the institution of the hospital cannot be understood without acknowledging that, outside the institution, exists a project of society that he defines as 'public hygiene'. In his words 'this kind of method entails going behind the institution and trying to discover in a wider and more overall perspective what we can broadly call a technology of power' (Ibid.). The question in this thesis is to verify if there is project of society behind PrEP practices and, if so, whether the gay population is targeted in ways that other populations are not. I argue that, in fact, it is through sexual health and HIV preventive practices that the HIV prevention assemblage can be understood as part of

the larger public hygiene project. This is not, per se, a negative aspect, and it certainly allows for the analysis of technologies of power, the tensions between the regulatory agents and the governed, and, as will be explained in chapter five, the tensions between the concepts of the responsible gay citizen and the irresponsible one.

The second displacement concerns the question of the function of institutions. Foucault points to the prison as an example of an institution that survives regardless of its failures to achieve its stated/ostensible goals, such as the ending of criminality or successful rehabilitation. Foucault states that prison's 'history is undoubtedly not governed by the success and failures of its functionality, but is in fact inserted within strategies and tactics that find support even in these functional defects themselves' (Ibid., p.118), noting that 'after a century and a half of "failures", the prison still exists, producing the same results' (Foucault 1977:277). In this context, using governmentality as a methodological tool consists in shifting the focus from the function of the institution to the strategies and tactics that support such an institution (Foucault 2007:118).

Thus, as happens with the prison or the state, some social entities within the HIV assemblage are not being governed by their successes and failures but find support *even in these functional defects themselves*. A clear example of this is that even though HIV is a manageable condition since the advent of antiretroviral treatment in 1995, thousands of people in the world keep dying from illnesses related to it. Access to antiretroviral medication and information does not properly arrive to those who need it the most. In this sense international organisations such UNAIDS seem to find support even when its functionality is questionable. The functional defects are reflected in the statistical reports that UNAIDS itself updates yearly and that show the failures of their HIV prevention and treatment interventions. As Stefan Elbe commented: 'To this end, UNAIDS also provides – in a manner that recalls England's 19th-century "Blue Books" – annual updates on the global state of the AIDS pandemic, and

endeavours to keep up-to-date information on HIV prevalence amongst adult populations for every country' (2005:407). In England and other countries in the UK, Public Health England publishes regular documents on public health interventions for the future, such as for example: 'HIV in the United Kingdom: Towards Zero HIV Transmissions by 2030' (PHE 2020). Moreover, even in the case of the PrEP response in England, as will be seen in chapters three and seven, there are populations that are not benefiting from such intervention and remain vulnerable to HIV. Failing to address the structural problems responsible for the advance of HIV is a functional defect in itself which, however, allows the HIV/AIDS assemblage to continue existing.

The third and last displacement affects the object of the disciplines that are related to the social field, such as medicine or law. According to Foucault, it is necessary to acknowledge that disciplines have created objects of study, observing that 'certainly we can say that madness does not exist, but this does not mean it is nothing' (Foucault 2007:118). Thus, there is the figure of the dangerous individual who needs to be governed, but it is through a process of subjectification that these individuals are being created on a large scale. The parallelisms with the object of the HIV assemblage are clear: although the entire gay population is the object of subjectivation through the promotion of PrEP practices, those who engage in riskier behaviour, those who refuse to follow the safe-sex guidelines, are the ongoing subjects of study for the simple reason that they avoid being governed. Moreover, this displacement can also be applied to the HIV assemblage since it refers to a displacement from the object of study to the field of study created. In this case, we can witness a displacement from HIV itself to the creation of HIV prevention studies, which have led to the creation of several new medical social subjectivities.

Governmentality and self-governance as methodology to analyse PrEP practices

Mitchell Dean lists four aspects that are necessary to consider in the analysis of 'the ethical government of the self' (Dean 1999:17): ontology, ascetics, deontology and teleology. All of these are dimensions that shape the structure of the moral experience of sexual pleasures (Foucault 1990), but they can also be applied to the self-administration of Truvada. The first aspect is the ontology of the matter to govern; this means *what* is governed. According to Dean, 'it might be the flesh in Christianity, the pleasures in ancient Greece, or the 'soul' of the criminal in modern penology' (Dean 1999:17). Through the self-administration of Truvada, one can govern the flesh, the pleasures *and* the soul. Thus, on a molecular level, the self-administration of Truvada governs the response of the immune system to HIV through the release of a combination of reverse-transcriptase inhibitors (Tenofovir) and nucleoside reverse transcriptase inhibitors (Emtricitabine). From this molecular level, the body is transformed into a strategic discursive act apt for the discussion and dissemination of gay governmentality practices. The pleasures, or sexual practices, are also governed, since the problematisation of the moral conundrum linked to barebacking practices in the realm of HIV prevention is negated through the use of Truvada

In this sense, the practice of barebacking, which is classified as a high-risk practice, is key to understanding processes of gay governmentality in the PrEP era. [The practice of] Barebacking, which has been defined as 'intentional condomless anal sex in HIV-risk contexts' (Carballo-Diéguez and Baumeister 2004:1), is a consensual and conscious practice in which the disclosure of the HIV status of participants is irrelevant. What is relevant to this practice is the absence of condoms, which strongly disrupts HIV prevention discourses – the very discourses that paradoxically produce the 'notion of transgressive bare-backing' (Russell 2005:156).

Within the moral climate imposed upon the gay population in the realm of HIV, those who engage in barebacking are subject to moral judgments and stigma. In his book *Unlimited Intimacies*, Tim Dean states that 'the very existence of bareback subculture potentially legitimates discrimination against those who are (or are perceived to be) HIV positive. Needless to say, the bareback phenomenon endangers public funding for aids research, treatment, and education' (2009:10). Dean's statement reflects the juxtaposition of morality and economics that is characteristic of neoliberal governments. By failing to make the right choices, not using condoms in the case of the barebacker, the latter jeopardises not only his own health but also public funding for AIDS, since treatment for HIV is considered an expensive one. In terms of neoliberal thought, the lack of morals of the barebacker is translated into a burden for the state. However, eleven years after Tim Dean's statement, it is possible to provide evidence that bareback subculture did not endanger public funding for AIDS research, treatment, and education, but, on the contrary, boosted it. As the research conducted for this thesis will demonstrate, barebacking is being stripped of the negative connotations of previous years and is now an almost healthy practice, as long as you engage in PrEP.

Secondly, [the analysis of the ethical government of the self] ' involves ascetics, concerned with how we govern this substance' (Dean 1999:17). PrEP requires a daily dose of two antiretroviral drugs in a single tablet and its effectiveness depends largely on the adherence to the treatment. Thus, the level of protection depends on the ability or willingness of the person to take Truvada every day. Such a regime of adherence might be translated in terms of self-discipline. One can argue that through the daily administration of Truvada, the body becomes disciplined, *docile* (Foucault 1977:138), but PrEP also requires surveillance. Thus, PrEP protocol requires HIV testing at least every three months, and kidney analytics at least once pe year. PrEP *ascetics* therefore involves self-discipline and surveillance.

The way in which the substance is governed is linked with the production of subjects and technoscientific identities. The medication governs the body, but it implies the governance of the bodies through discipline (adherence to the treatment) and surveillance (through trimestral blood tests to determine if the treatment is successful and to calibrate the effects of Truvada in other organs and tissues of the body). This combination produces a governed subject who is free to a certain degree because, regardless of bodily surveillance, there is still some autonomy: 'the governed are free in that they are actors, i.e. it is possible for them to act and to think in a variety of ways, and sometimes in ways not foreseen by authorities' (Dean 1999:13) In fact, surveillance is voluntary as will now be seen.

The third aspect 'involves deontology, concerned with who we are when we are governed in such a manner, our "mode of subjectification", or the governable or ethical subject.' (Ibid., p.17). The governable subject of the pharmaco-regulatory practices is the pro-active subject, willing to engage in such practices while developing a sense of agency that was previously perceived as inactive or non-existent. In this sense, technologies of agency are those 'technologies of government that seek to enhance or deploy our possibilities of agency' (Ibid., p.167). As Dean points out, these technologies are frequently directed at those "targeted groups" who are perceived to be at risk and therefore need 'to transform their status to make them active citizens capable, as individuals and communities, of managing their own risk' (Ibid., p.168). The internet-based community *PrEP Facts: Rethinking HIV Prevention and Sex* exemplifies one assemblage that works as a technology of agency. Although the role of this community in the dissemination of PrEP will be discussed further below, the mission statement posted on their Facebook page *PrEP Facts* is relevant regarding these technologies of agency. The group administrators assert that: 'the intention of this board is to support discussions, debates, questions, and concerns that promote fact-based information, understanding, respect,

and compassion.'[3] This statement characterises the group´s members as active subjects whose actions entail a transformative project of self-government.

The fourth aspect of the analysis of the ethical government of the self 'entails a teleology, concerned with why we govern or are governed, the end or goal sought, what we hope to become or the world we hope to create, that which might be called the telos of governmental or ethical practices' (Ibid., p.17). This aspect also relates to the production of subjectivities, since the reasons to engage in practices of self-governance are intrinsically linked to the visions of the self that are pursued by those who become involved in self-governmental practices. People who engage in PrEP practices might envision the future as a time in which HIV doesn't belong to the realm of sexuality and seroconversion is no longer a scary word because it will never happen. They also embrace a sense of responsibility towards the wellbeing of the gay community.

In conclusion, this section on governmentality has claimed that, as a social theory it is extremely pertinent for the framing PrEP practices, but it is also relevant for the analysis of such practices. Therefore, the analysis of the government of the non-positive antiretroviral gay body will benefit greatly by (i) looking at the power relations emerging from the HIV/ PrEP assemblage in England and directed to the gay population and (ii) analysing the moral and ethical questions related to discursive practices of the government of the self.

Medicalisation / Biomedicalisation: constructing the biomedicalised gay body

Although the medicalisation of sexual behaviours has been traditionally regarded with suspicion by social scientists, later theorists point out that medicalisation may be productive of identities and practices that have had a transformative impact on the way people come to

[3] https://www.facebook.com/groups/PrEPFacts

understand themselves in relation to medicine. In this sense PrEP practices constitute a clear example of how gay men have engaged with medicine in transformative ways. But how is medicalization understood? The following section provides a brief review of different perspectives on medicalization, with the aim of understanding the heterogeneity with which different authors have treated this concept.

The term *medicalisation* describes processes by which issues previously considered outside the realm of medicine become defined and treated as medical questions, usually in terms of illnesses and disorders (Conrad 2007). The process of medicalisation has led to 'the expansion of medical jurisdiction, authorities and practices to new realms' (Clarke 2003:161). The term medicalization was also understood as the ways of interpreting everyday life events in terms of health and illness (Zola 1972). Since the first sociological studies began on this phenomenon in the late 1960s, perspectives on medicalization have been mainly critical. Most analysis has focused on elucidating the negative impact of medical authority on individuals' conduct or conditions that had previously been under legal, political, or religious surveillance (Sholl 2017). As Sills has stated, 'medicalization has resulted in extending immunity from punishment to certain culprits. However, it would also seem 'that medicalization is one of the most effective means of social control and that it is destined increasingly to become the main mode of social control' (1968:391). This popularly accepted approach to the concept was challenged by the sociologist Nikolas Rose (2007b), who argued that 'medicalisation has become a cliché of critical social analysis' (700). Although the power of medicine over life itself is certain, Rose argues that it is necessary to acknowledge that 'medicalisation has had an even more profound effect on our forms of life: it has made us what we are' (Ibid.,p.702). In this sense, biomedicalisation perspectives certainly acknowledge the positive effect that techno-science and biomedicine have over certain bodies, particularly male bodies. In relation to this, it has been stated that 'compared to the original medicalization thesis that assigned

women [and I would add gay men] the status of victim, the target of biomedicalization is not to victimize men but to keep them from any possibility of victimization, such as failing masculinity' (Riska 2010:162).

Challenging overly simplistic understandings of medicalization, Marcel Verweij is concerned with the moral dimensions of the concept. The author posits that 'the term medicalisation is used to express a number of more or less vague moral intuitions concerning preventive medicine', and that, indeed, the role of preventive medicine in medicalization is problematic (Verweij 1999:90). Some analysts have argued against the fully negative perspective. Again, Rose (2007b) indicates that processes of medicalization have an important effect on the way we live our lives and argues that by the early twenty-first century individuals 'describe themselves in the languages of health and illness' (701). Ultimately, medicalization processes play an important role in the creation of new identities. This is true in the case of many men who define themselves as 'homosexuals', a medical category originating in the nineteenth century. More recently, a similar phenomenon of self-naming is evident among men who define themselves as 'poz' (positive), 'HIV' or 'negative' in the context of HIV medicine, as well as in the context of negotiating sexual exchanges. Medicine, in fact, is the focal point in the creation of changing identities and (bio)medicalization perspectives; this, as well as the intensification of the role of biomedicine in the transformation of identities and bodies, will be discussed in greater detail later in chapter three.

Biomedicalisation perspectives

Up until now the concept of biomedicalisation has been used in this thesis to describe techno-scientific methods applied in clinical practices within the realm of HIV prevention. However, the concept of biomedicalisation is also used by social theorists to describe a complex phenomenon that involves the intensification of medicalization, meaning the intensification of the role of medicine in everyday life. Due to techno-scientific innovations in biomedicine in

the last four decades, this intensification of the medicalization of behaviours and conditions has merged into what has been defined as *biomedicalisation*. Biomedicalisation is, then, a broader perspective of medicalization, and it is mainly concerned with the following processes: (1) the privatization and commodification of health; (2) the focus on health, theories of risk, and practices of surveillance; (3) the expansion of techno-scientific practices in the realm of biomedicine; (4) the diversification of sources in the production and distribution of medical knowledge; and (5) the transformation of bodies and the production of new techno-scientific subjectivities (Clarke et al. 2003).

In the United States, where the concept of biomedicalization originated, these processes consolidated around the end of the 1980s, coinciding with the late stages of Ronald Regan's new right administration (Riska 2010). But it is necessary to state that those five processes are characteristics of other advanced liberal democracies as well, since scientific knowledge is largely globalised. As stated by a prominent advocate of the theory, 'the dynamics of biomedicalization travel widely' (Clarke 2010:381). In England, some of these processes began to rise with the first implementation and development of neoliberal doctrines in the first half of the 1980s, and it was during that decade that those processes converged and began to develop with more intensity, a process which continues to the present moment. It is imperative to understand that those five processes are not isolated one from each other; rather, they interact with each other as a dynamic assemblage.

In response to this theory of biomedicalisation as an assemblage of processes, Conrad argued that 'biomedicalisation is a much broader concept than medicalisation and emphasises a more extensive set of changes than is usually meant by medicalisation, thus in my view compromising the focus on medicalisation itself. Yet it seems clear that significant changes in medicine have had a significant impact on medicalisation' (2007:14). Although it may seem that somehow the focus on medicalization is lost, the concept of biomedicalization presents

itself as a richer theoretical framework for the analysis of shifts in HIV prevention, since the phenomenon of PrEP takes part in each one of the processes described by Clark et al. above. In what follows there is a basic description of each process and why PrEP practices fit those processes.

1. The privatization and commodification of health: These two concepts are usually linked together to highlight the impact that economic perspectives have in the development of health services. As will be explained in more detail in chapter 3 the privatization of health is an historical process that can be traced back in Britain to the origins of the NHS and that has contributed to the reconfiguration of patients as consumers. It is, however, in the genitourinary and sexual health clinics (GUM) that the commodification of sexual health services offers a clear example of such commodification. Part of the process of implementation of PrEP in England has to do with its delivery as a medical commodity that is offered in sexual health clinics to all gay men who are at risk of contracting HIV. Do-it-yourself PrEP practices consisting in buying PrEP online have contributed in the greatest way to frame PrEP as a medical commodity.
2. The focus on health instead of illness and development of theories of risk and surveillance.

   PrEP embodies a prevention technology that focuses on the health of those who engage in taking antiretroviral drugs for prevention. The bottom line here is that antiretroviral drugs are used not as an HIV treatment but in order to prevent HIV taking hold in the body. In this sense, in England, PrEP has to be understood as a biomedical intervention targeted originally at gay men who have been historically considered the most at risk. As I will frequently reiterate in this thesis, biomedicalisation requires the active role of gay men in embracing the intervention. Thus, it is not necessary to be ill, or to present

symptoms, to perceive oneself at risk. This the case of gay men who do not live with HIV but still consider themselves at risk enough to take antiretroviral medication, in what can be interpreted as pharmaceuticalisation of risk. Moreover, PrEP can be deployed as a practice case for surveillance theories from the perspective of group risk (Douglas 1986) and from panoptical interpretations of self-surveillance (Foucault 1977; Preciado 2020).

3. The expansion of techno-scientific practices in the realm of biomedicine. PrEP is part of the history of the development of pharmaceuticals. This development has brought about less toxicity in drugs and new forms of drug presentation such as the single-pill drug including several antiretrovirals that have made easier treatment adherence. The expansion of techno-scientific practices is also present in the design of the different PrEP-related clinical trials. The computerization of the participants' clinical data is a core part of these clinical trials and a valuable resource to produce scientific knowledge.
4. The diversification in the production and distribution of knowledges.

   The PrEP phenomenon has led to a redistribution of scientific knowledge about HIV. In a way, it has helped to socialise the production of knowledge, as PrEP users have taken an active role in distributing information on various aspects surrounding PrEP practices, such as PrEP sourcing, types of PrEP regimens, etc. Thus, in addition to the traditional vertical model of knowledge production that would include doctors, HIV/ AIDS organizations, journalists, and others, a horizontal network of knowledge transfer has emerged among PrEP users. This phenomenon has been driven by technological developments such as dating apps and (other) internet forums.
5. The transformation of bodies and the production of new techno-scientific subjectivities.

   The role of antiretroviral drugs in the production of sexual subjectivities has been acknowledged by social theorists, especially in the case of antiretroviral drugs for

treatment (Lloyd 2018). In the same fashion, in the case of antiretroviral drugs for prevention it seems logical to hypothesise that PrEP, by working at a molecular level, transforms, enhances or at least complements the response of the immune system in the bodies of those who take it. The effects that the drugs have on the body has a clear impact on the way users relate to them. Thus, as we will see in chapter 3, in England some people refer to themselves as PrEPsters in a clear statement about the role that antiretroviral drugs play in their lives. In other words, engaging in PrEP practices becomes part of their identity.

Methods

Obtaining rich qualitative data is recognised as one of the best ways to develop in-depth understandings of complex individual and subjective experiences. Thus, this project uses a qualitative mixed-methods research design, which includes oral history interviews and archival research. Together, both sources provided extensive primary data for the analysis of PrEP practices, attitudes regarding HIV/ AIDS activism and the biomedicalisation of HIV prevention methods. The following is a description of the methods employed:

Oral history interviews

The voices of those who participate in a historical phenomenon help to create a deeper, richer and more complex understanding of such moments. Critics of oral history argue that memory is a subjective process and that factual data revealed in this type of interviews is not always reliable. However, this thesis is informed by a rich body of research on oral history, memory and subjectivity which has already taken on said empiricist critics (Passerini 2017; Kennedy and Davis 2014; Frisch 1990). Therefore, I consider that for a project on processes related to the use of antiretroviral medication, oral history is an excellent tool. In this thesis, as important as it is to create a reliable description of the history of a biomedical interpretation, it is equally

important to create a history of the production of subjectivities within that biomedical intervention. Thus, some of the questions that this project aims to respond to are 'what forms of persons, self and identity are presupposed by different practices of government and what sort of transformation do these practices seek'? (Dean 2010:43). The answers to these questions can be facilitated through oral history interviews that are designed to address aspects related to the practices of self-government and identity.

As expressed by Lynn Abrams, 'an oral history source based on memory offers up insights into the interplay between the self and society, between past and present and between individual experience and the generalised account; in addition, it will often provide emotional content that a written version of the same story will not' (2010:81). In this sense, and if well conducted, an interview can supply very valuable data. Subjective memories form part of the background against which people elaborate decision-making and produce meaning. For example, many participants elaborated their responses regarding PrEP practices as linked to childhood memories or traumatic experiences. The factual details of those experiences are not as important for this project as how the interviewees linked those experiences with PrEP practices. The following testimony provided by an AIDS activist is a good example of why oral history is useful to understand processes of identity formation.

> Just as a kind of coda, we were talking in conclusion about fear and the opposite side of fear which of course is hope, and fear of death on the part of people who were infected, and fear for our friends and for ourselves. But also living with fear, and living with anxiety, which people have to learn to do, always, in different ways as we get older . I certainly remembered a story that I didn't tell when I was in Brighton, which I meant to. One day my friend **X** had gone out and met with somebody I can't remember where but somebody about our age, (he) was very attractive, maybe a year younger. Let's say we are at the age twenty and this boy is nineteen. And he was in Brighton and he was on the game (scene), and he was on the scene a bad way, and he wasn't doing heroin, but he would do speed and he

> was wobbly to say the least. And it turned out that he was in Brighton because he had a boyfriend who was older than him. This really old man, he was like twenty-six (laughs) and they had an affair, they met when […] he was twenty-five and he was like sixteen or something, long way below the age of consent in those days. And the boy's parents have found out this was going on, and they informed the police and they insisted, and they demanded that the other man be arrested, which he was, and he was in prison. He was sent down, he got three or four years, although the relationship was entirely consensual. He was in Lewes prison, and he killed himself. And the younger boy, because he was now eighteen, nineteen and left home of course, but he was in a very bad way psychologically. Now, I've told **X** this story years later, he doesn't remember, which is extraordinary to me. So, it's one of those stories that I just have it as a memory. I believe it, because it's a memory that I seem to have and it's a memory that's always been with me, I think. **X** doesn't share it which surprises me. But there it is […] It's a terrible memory, it's also inspiring in some ways to me, in terms of motivating me, emotionally, in the kind of political mode [...] but motivating me anyway. And there were similar stories in the epidemic. You know, going to flats where, somebody was dying, and you went to help on their way, all those awful memories which are very hard for lots of people. Or just memories of saying goodbye to people you love. Hard memories. But they all fit together some way, in some weird strange way, but they also made death less frightening. (Jeremy 2017)

I have used this excerpt to illustrate the value of an oral history testimony in which the precision of what is told, including the reality of what is told, can sometimes be less important than the value that the person gives to that memory. In this specific case, a painful memory plays a very important role in the formation of a political gay identity. In other words, subjective memory is 'capable of saying a great deal about how the past does or does not figure in our lives and this in turn tells us about both history and ourselves' (Frisch 1990: 22).

This project included two set of interviews. The first involved fifteen in-depth interviews with people who take antiretroviral medications as a preventive method (PrEP). For the PrEP group the criteria were: (i) to identify as gay man, (ii) to be resident in England and

(iii) to be on PrEP or have been on PrEP. Among this group there was a person involved in HIV prevention for more than twenty years and highly committed to the implementation of PrEP in England. There were also two men who identified themselves as trans men. The increasing emergence of trans men on the gay male scene, including the sex scene, is a significant historical challenge from the early days of AIDS. The highly biomedicalised experiences of these men are the source of rich insights and contributed to complicate definitions of 'gay sex' not only as a practice, but also in terms of HIV prevention.

The second group of interviewees (eight in total) were gay men who directly experienced the AIDS epidemic in England and participated as policy makers or influenced policy making in relation to AIDS/the epidemic. Out of the eight interviewees, five became HIV positive before 1995, one circa 1995 and one in 2012, meaning that their relationship with antiretroviral medication is one of treatment and not prevention; this is significatively different from those in the PrEP group. Five of these men worked in or for HIV organisations during the 1980s and/or 1990s. This group is clearly distinctive from the first, in that they accumulated a huge expertise on HIV/AIDS policy making.

Recruitment was made online through different channels. For the PrEP group, two men were recruited through gay dating apps, namely Growlr, Grindr and Scruff. The rest were contacted via personal messages on Facebook pages related to the dissemination of data and the acquisition of PrEP via the internet. Recruitment for the second group included snowball sampling. This first group recruitment method allowed for some variety in the interviewees, while the second group was more homogenous.

Location of the interview

The place of the interview can shape the participants' responses. In fact, 'the choice of interview location (who chooses and what place is chosen) is not just a technical matter of convenience and comfort. It should be examined within the social context of the study being

conducted and analysed as an integral part of the interpretation of the findings' (Herzog 2005:25). In regard to this project, I tried to accommodate the needs of the participants as much as I could, and I travelled to the homes of the participants when they required it.

The interviews took place in London, Brighton, Leeds and Deal. Most of the interviews were at-home interviews, but I also did one at the Sussex University library and another at a participant's allotment in London, since interviews at home were not possible. Three interviews took place in the offices of two different HIV charities in London. Only one of the PrEP users' interviews took place in HIV-related locations, specifically at the Terrence Higgins Trust offices. This person worked as a sexual health promotor targeting black populations. For the rest of the interviews, I was not too worried about how the place could inform the interviewee's responses. However, two interviews were conducted at my home as this was requested by the interviewees, which could have affected the responses in replicating HIV prevention discourses. I let these two participants know that I had no links with HIV charities. I followed the health and safety regulation protocol of the University of Roehampton, including letting a third person know when and where the interviews were taking place.

The structure of the interviews

For the first group, the PrEP users, the interviews were semi structured as a way to gather information that could be excluded by a rigid structured interview (Portelli 2003). I had prepared a set of questions related to the theoretical framework that have informed the analysis of this thesis. The theoretical framework, which has been thoroughly discussed, entails a combination of theories in biomedicalization and Foucauldian approaches to governmentality. These are questions about the personal understanding of risk, personal responsibility, the use of new technologies, and the commodification of sexual services. The script of the interview was structured by the following sets of questions:

1. Basic biographical questions
2. First lived experiences related to HIV / AIDS
3. PrEP-related questions
4. A last question following explicitation techniques: " Who are you when you are taking the pill"?

Prior to starting the interviews, I asked the interviewees if they would like me to disclose the reasons why I wanted to do the interview as well as give them some information about my life. This information included some biographical data, my coming out process and the reasons why I was interested in PrEP and the history of the HIV epidemic in England. The decision to disclose this personal information was based on the idea of balancing power between the researcher and the participant; moreover, for the participants, being interviewed can also be perceived as something valuable. To illustrate this point, one participant suggested that he had the feeling that he had disclosed more relevant information about his life in this interview than he had disclosed in weeks to his therapist.

The first set of questions included questions about the place where the interviewees had been raised and how it was to grow up there. I did this set of questions because the project deals with the production of gay identities as well as the subjective ways of experiencing those identities; I also asked what it meant to be gay in those days and how the coming out process was. *How* questions were prioritised during the interviews as these revealed dimensions of government (Dean 2010:39). Some of the questions related to where and how they were raised would prove important for some of the participants in relation to their future PrEP practices.

The second set of questions were aimed at understanding the relationship between the lived experiences of the participants in relation to being gay and HIV/AIDS. The starting point for this set of questions was to ask the participants when the first time that they had heard about HIV/AIDS was. Since the answers would vary depending on the age of the participants, the follow-up questions would engage with the response given by them.

The third set of questions were those related to PrEP. Again, the starting question had to do with the first time they heard about PrEP. Regardless of the path that the answers could lead the interview, and as I mentioned earlier, I prepared a set of guiding questions that dealt with the governmental/biomedical aspect of PrEP. Among these questions were:

- How do you get PrEP? How important, in your opinion has the internet been for you to access PrEP? Would you talk a bit about it?
- Do you use apps like Grindr, Scruff, Growlr (if so, do you use them to find other people on PrEP)? What do you think about these apps?
- What are your feelings about having to buy your own PrEP?
- Do you use sexual health services? How would you like to be referred to? As a patient, as a user or as a consumer of sexual health services?
- Have you thought about getting on the IMPACT trial?
- Can you tell me a bit about your emotions the first time you were on PrEP?
- How does PrEP feel in terms of sexual freedom? Do you feel you are freer now than before?
- How would you define risk (not necessarily in relation to sexual practices)?

Some of the testimonies of the interviewees spontaneously addressed these themes, but since part of this research aimed to understand how the testimonies of gay men using PrEP fit or challenged biomedicalization theories, I introduced these questions to those who did not talk about this.

The last question was an experimental question inspired from a workshop on explicitation interview techniques that I took at the University of Roehampton. One of the objectives of the explicitation technique is to make someone describe in detail a lived action. The lived action that I choose was the moment that the interviewee took the pill of the antitretroviral medication. I warned the participants that the last question was an experimental question and that they were free to answer it or not. The formulation of the question required

inviting the participant to take a moment to remember the last time that he took the pill. I guided this moment by asking questions about the place and the time that they were taking the pill. Once they had confirmed that they remembered the situation, I asked them 'who are you when you are taking the pill?' I asked this question for two reasons: firstly, I wanted to know how the answers fit the notion of a technoscientific identity in relation to PrEP practices. Secondly, as a researcher, I think that it is important to give the opportunity to the participants to define themselves in their own terms. When concluding the interviews, I thanked all the participants and asked them if they wanted to add something. Some interviewees added some thoughts to the interview, although most of them said they were happy with their answers.

For the second group of interviews I followed a different script since these men were using antiretroviral medication for treatment and many of them were active HIV/AIDS community members. Most of the participants in this group had been using ARV medication for longer than twenty years when the high toxicity of the medication made adherence to the medication regime challenging. The interest in this group was not as much on the biomedicalisation aspects of HIV prevention or treatment as on their experiences with antiretroviral medication and their role as HIV/AIDS community activists. The interviews followed the format of the life story as well, but since some of the participants were well known in the history of HIV activism some questions were tailored to their career in activism. The life-story format included questions related to gay identity in childhood and the places where the interviewees were born and the process of coming out of the closet. They also included questions about seroconversion and antiretroviral treatments. When finishing the interview, I thanked the interviewees and asked them if they wanted to add anything else to their testimonies.

Throughout this thesis I have pseudonymized the identities of all participants with the exception of HIV/PrEP activist Greg Owen who explicitly granted me permission to use his

real name. This is due to two reasons: (i) some of the facts he narrates have already been published in public media and do not constitute a danger to him, and (ii), other participants named him in their interviews since he is a central person in the process of implementation of PrEP in England, complicating the anonymization process and making difficult the reading of the thesis. The identity of the rest of the participants, PrEP users and some notorious HIV community activists, has been protected under pseudonyms

Archival research

Archival research was a fundamental activity in the search of primary data for this project. This primary data included personal testimonies of gay men concerning the AIDS epidemic in England, as well as gay men's opinions about the HIV/AIDS response before antiretroviral medication was effective. Written documents, diaries, pictures and other memorabilia helped to provide a historical perspective on the development of antiretroviral treatment and attitudes towards HIV and AIDS in England throughout the epidemic. I visited several archives, including The Keep (Brighton), the London Metropolitan Archives, the Bishopsgate Institute (London) the University of San Francisco in California, and the San Francisco Public Library. The Keep in Brighton contains two different collections of very substantial testimonies about the lived experience of gay men during the epidemic. The first collection is the National Lesbian and Gay Survey (NLGS) which is deposited within the Mass Observation archives. The NLGS spans a period of twenty-eight years, from 1986 to 2004, and 724 participants answered questions on many varied subjects. Directives proposed before 1996, when antiretroviral treatment became effective, proved to be related to the aim of this study. Ken Barrow, the promoter of the NLGS and himself a Mass Observation participant, provided volunteers with a directive containing the following questions, among others:

> How do you generally feel about AIDS? Does it scare you? Has the crisis infringed on your lifestyle in any way? Do you know about the safe-sex guidelines? Have you been able to implement them as part of your sexual activity? Do you find it difficult to persuade your partner to have safe sex with you? Have you found it impossible to give up sexual activities, however unsafe, that you have always enjoyed?

The answers submitted by the participants constitute a rich source on the subjective experience of living through an epidemic that brought death to the forefront. As a result of this research, I gathered around fifteen thousand words of testimonies related to gay men and health. These were mainly testimonies that revolved around emotions towards AIDS (gay men talking mostly about fear of AIDS), experiences of testing for HTLV-III (the former name for HIV), opinions about government attitudes towards AIDS research, personal experiences with AIDS and AIDS activism.

At the University of San Francisco Library, I found the box on 'Guerrilla Clinic' very interesting. The guerrilla clinic was formed by a group of AIDS activists whose goal was trying to source unapproved or experimental drugs in Mexico for people living with AIDS. This group would sell the drugs at a non-profit rate. The box contained press cuttings related to the guerrilla clinic, letters to doctors from the guerrilla clinic activists and records of instructions on how to obtain chemicals to synthesise experimental drugs at home. The data extracted from this archive supported the idea of gay men being active agents on the biomedicalisation of gay sex and provided a clear historical antecedent to the ways in which gay men in England engaged with buying PrEP.

Reflexivity: my position as researcher

My position as a researcher and the perspective from which I designed this thesis was strongly informed by my sexual identity, my relationship with antiretroviral drugs and my cultural and

social background. Far from a polarised insider or outsider position, these three elements granted me a dual insider /outsider stance that at times clearly benefited the project whereas at other times it complicated the data analysis. It became necessary to acknowledge that 'both perspectives have the possibility of distortions and preconceptions of social reality' and that it was my responsibility 'to evaluate the distinctive advantages and limitations of each perspective in relationship to the problem of research at hand' (Kikamura 2003:141). In what follows, I will address the evaluation of such positions.

Being gay helped me during the recruitment process. Thus, getting in contact with gay men in England was initially not complicated. It proved, however, more challenging to recruit gay men who were on PrEP. Moreover, sharing a gay identity with the interviewees made the process of talking about gay sex and sex practices easier. Having a background in the study of sexual dissidences also helped me to talk about sexual practices with openness and without judgment. I believe that most of the participants were very comfortable talking about their sexual lives, which enriched the data. In this sense, having an insider position shaped the research and the interview process in a positive way.

Having been in a long term-relationship with a person who is HIV positive affected the way that I did the interviews and analysed the data. I shared the anxieties of those participants who were afraid of becoming HIV positive before they took PrEP. At the same time, I also share with them the benefits of the antiretroviral drugs once the results of the PARTNER trial were published. This study was conducted in 75 clinic sites with the participation of serodiscordant partners, meaning only one of them was living with HIV. The PARTNER study concluded that is not possible to transmit the virus if the viral load is undetectable, meaning that condomless sex was not a risk practice when the HIV partner was using effective HIV antiretroviral medication.

Although it was my partner who was taking the HIV medication, I benefited from antiretroviral medication in a similar way that some of the participants talked about PrEP. For example, we did not have to use condoms when having sex, which eased our sexual relationship in various aspects. In relation to this project, I was, on one hand, an insider within the world of antiretroviral medication. I witnessed my partner taking his medication every day, and I was aware of the benefits of the medication for both of us. On the other hand, I was an outsider in the world of the HIV-negative gay men who were taking antiretroviral medication and I had a genuine curiosity to know about their reasons for taking PrEP. During the process of this PhD I have considered taking PrEP myself. Again, I think that somehow the outsider position complicated the project but made it richer and shaped the way I did the interviews.

My idea of activism is largely shaped by my own years in the Basque Country, when I participated in the antimilitary movement and the squatter movement. It also comes from witnessing the Basque ecologist movement and Basque nationalist movement in which several friends and many acquaintances participated. All these movements involved, at different moments, strategies of civil disobedience and direct action. As an antimilitary activist, I participated in the *insumision* movement, becoming an *insumiso* myself and refusing to go to the mandatory military service. For this I was sentenced 'to the penalty of six months in prison and ten years of absolute disqualification, with the accessory suspension of all public office and right to vote during the time of the sentence' (BOE 2001). Although I did not serve time in prison, this experience shaped my life's outcomes and my views of the consequences of being an activist, since 'ten years of absolute disqualification' prevented me from having access to any public job, or public scholarships in my home province of Navarre. That sentence was a form of civil death. As an even more active participant in the Basque squatter movement, I linked the idea of activism to everyday practices of civil disobedience, since the spaces in which I worked were illegally occupied. In sum, my idea of activism was linked to two main

ideas: firstly, activism carries hardships for one's future and secondly, activism is almost always linked to civil disobedience strategies. Moreover, although the antimilitary movement was strongly supported by a large section of society and the press, the squatter movement was often stigmatised and classified as anti-social, meaning that there was no social recognition for such activism.

These views largely contrasted with the representations of PrEP activism in England. The representatives of PrEP activism were clearly well treated by the media, and those who participated in PrEP activism did not see their outcomes in life threatened. For example, PrEP activism is sometimes circumscribed within the professional ambit, which means that far from becoming a threat to activists' financial status, sometimes it can help to improve it. There was also no civil disobedience in their strategies. There were some demonstrations, which in my opinion is a civil right, but still there was not much to be concerned with in regards to the legality of the movement. My interest in reflecting on my situatedness emerges from my anxiety in interviewing some participants whose practices of activism clashed with my own conception of activism. I attribute this critical tension to a difference in situatedness. The term situatedness was introduced by Donna Haraway (1988) when talking about feminist objectivity, stating that knowledge is situated, meaning that knowledge comes from the specificities of the researcher or the theorist. I had this present at most times when analysing and conducting interviews with PrEP activists. Yet, from that position, I was able to acknowledge the level of creativity, effort and extra hours put into work, in what clearly constituted another type of activism and could not be dismissed as such. In this sense, my own situatedness constituted a threat to the quality of this work and I had to be conscious of it, both in the collection of data as well as in the analysis process.

Conclusion

The reason for combining assemblage theory and governmentality, which are theories on

power dynamics, and relating them to the advances of the role of medicine in society, is to make clear the complexity of a phenomenon that initially seems to be the simple act of taking a pill. By considering these three perspectives, it is easier to comprehend the intricacy behind PrEP practices. Moreover, these three theories are intimately linked to the questions that motivated this project. In this sense, as important as it was to answer those questions, this thesis is also an attempt to challenge and to delve more into governmentality and biomedicalisation theories. This thesis uses PrEP practices in England as a contribution to the field of governmentality studies, aiming to consider pharmaco-regulatory practices as a key factor in the governance of gay population in England. On the other hand, biomedicalisation as a social theory offers a great starting point to analyse PrEP practices, but this thesis seeks to test the pertinence of such theories in England, a country with similarities to, but also differences from, the United States, the place in which biomedicalisation theory was created.

Independent of the heavy debt to Foucauldian concepts and terms, this is not a purely Foucauldian work. It works with Foucauldian concepts and sometimes challenges them, as Foucault himself did with his work, when for example power was characterised in multiple, sometimes antagonistic, ways. The same could be said of biomedicalisation theory. This thesis draws on the concepts of Clarke and colleagues in order to analyse PrEP practices. However, as the following chapter aims to prove, biomedicalisation theory is as challenged and embraced in different ways by the testimonies of the participants. Thus, this thesis uses three different theories, not only as framework for a phenomenon, but sometimes, as a methodology to analyse such phenomena.

Chapter 3: The non-positive antiretroviral gay body: the biomedicalisation of HIV prevention in England.

As mentioned in the introduction to the thesis, PrEP represents a breakthrough from previous HIV prevention methods which were mostly based on the adoption of non-biomedical behavioural changes. These changes were widely adopted by gay men since the first years of the AIDS epidemic and included strategies for the prevention of HIV such as the normalised use of condoms, choosing sexual partners depending on their HIV status, or (serial) monogamy (Giami and Perrey 2012; Russell 2005). HIV prevention organizations also promoted other prevention strategies such as raising awareness about HIV status, increasing HIV prevention knowledge or providing information and condoms in sex venues for gay men, and testing (CHAPS Partnership 2011). The combination of these strategies seemed to work until 2001, when HIV diagnoses began to rise again until 2016. Before the emergence of PrEP in 2014, the aforementioned strategies made up the HIV prevention toolkit in England. The aim was to prevent HIV from reaching the body. However, for all those gay men who decided to get PrEP the aim was different. From now on, it is not a question of preventing the virus from entering into bodies, but a question of taking enough antiretroviral medication so that the virus, once in the body, cannot reproduce itself and take hold.

This chapter argues that the change from behavioural strategies to PrEP represents a further step in the history of the biomedicalisation of gay sex in England, contributing to the emergence of the figure of *the non-positive antiretroviral gay body*. As was mentioned in the introduction, this conceptual figure carries with itself a long story of medicalization, the history of the intervention of medicines in the bodies of men who have sex with men.

Moreover, I argue that this historical breakthrough in HIV prevention methods, as well as the emergence of the non-positive antiretroviral body is circumscribed within the socio-medical phenomenon called biomedicalization. As has been outlined in the theoretical section,

this phenomenon is driven not only by techno-scientific advances in biomedicine and developments in digital technology, but also by neoliberal globalisation and consumer culture that commodifies sexual health (Clarke et al. 2003). The determination of whether or not the (bio)medicalization processes of gay sexualities are perceived as positive or negative for those who engage in them will be analysed in depth in the following chapters. Rather, this chapter aims to understand the scope of these biomedicalization processes in the life of PrEP users in England, by drawing on theories of medicalization and biomedicalization, as well as testimonies given by PrEP users and promoters provided in oral history interviews. Thus, this chapter pays attention to the processes of commodification of HIV prevention, the role of theories of risk in PrEP practices, the role of PrEP in the production of new techno-scientific subjectivities, and the diversification of sources in the production and distribution of HIV prevention knowledge. These processes have contributed to the configuration of the non-positive antiretroviral gay body in England.

The commodification of Pre-Exposure Prophylaxis in England

This section explores the ways in which the economic dimensions involved in the implementation of PrEP in England are shaping PrEP-related subjectivities and practices. The key question addressed in this section is the following: Can antiretroviral drugs for prevention be understood as medical commodities? This section provides the historical context that frames the development of HIV prevention as a commodity, as well as locating the ideological origins that contributed to the appearance of the non-positive antiretroviral gay body. It is necessary to review the historical-political framework in order to understand how macro scenarios can affect individual practices in the realm of sexual healthcare, such as the large number of gay men buying generic PrEP online. This section also outlines the history of neoliberal attempts to privatise the NHS and the efforts to reconfigure patients as service users or (sexual) health consumers. This reconfiguration is a distinct dimension of the process of the commodification

of sexual health services in England.

From 'healers to dealers': Background of Buyer's Clubs and Guerrillas Clinics

The origins of buyer clubs and guerrilla clinics date back to the early years of the AIDS epidemic. These clubs came to proliferate in the United States as a reaction to the slow pace of the Federal Drug Administration (FDA) in approving drugs for the treatment of HIV. In fact, almost six years passed between the reporting of the first case of AIDS and the FDA's approval of the first drug for its treatment, AZT. It was in this context that *The Chicago Sun Times* reported that an 'underground network of guerrilla clinics has sprung up in more than 40 American cities, including Chicago, to dispense homemade experimental drugs to desperate AIDS patients fighting for their lives' (Wolinsky 1987). The phenomenon did not go unnoticed and the national media echoed the actions of underground networks. For example, *The American Health* magazine stated that guerrilla clinics were giving information about how to make homemade AIDS drugs or how to get the drugs and how to use them (*American Health* 1987). The phenomenon expanded to other areas in the world. An archived letter at the University of California San Francisco exposes the mechanics of these guerrilla clinics: 'Dusseldorf phoned me again this morning at 6am. They have obtained a kilo of DNCB from Fulga in Switzerland for only $16 and wanted immediately to start a clinic. X asked me to have you put this address and telephone number on all directories and mailings, etc.' (Elswood 1987). The nodes of the network reached places as distant as Japan, Munich and London.

Buyers' clubs proliferated independently or in cooperation with guerrilla clinics as illustrated here: 'Soon ddC was pumped out of basement laboratories and passed on to the buyers' clubs and from there, distributed to people with AIDS and HIV around the country' (Epstein 1996:139). Dideoxycytidine, commonly known as ddC, was one of the antiviral drugs, along with Ampligen, Glucan, DTC, AS 10 and other drugs, that the FDA was testing, but none

of them were licensed drugs for HIV/ AIDS treatment. The number of people estimated to be living with HIV and AIDS who were buying ddC by late 1991 was ten thousand. This number suggests that the phenomenon of buyers' clubs is of great relevance in the history of HIV and AIDS patients in the United States.

Some U.S. patients skipped buyers' clubs altogether and went to get antiviral drugs such as Ribarin in Mexico. In January 1987, the gay newspaper *Bay Area Reporter* wrote:

> Hope turned into despair and confusion last week for those who use – or want to use – Ribarin. The U.S. Custom Service imposed stricter standards on importation of the drug. Customs agents from Tijuana to Brownsville Texas confiscated Ribarin from many gay men last weekend. In some cases where people refused to surrender the drug, Customs agents denied them entry. (Jones 1987).

This article not only illustrates the practice of buying drugs outside the health structures of the country itself, but also shows the relationship between access to pharmaceuticals and issues of citizenship that would be echoed in future PrEP discourses. The foregoing proves that, historically, gay men have found ways to deal with their perceived lack of treatment for HIV and AIDS. But what happened in England? There is a lack of literature regarding the existence of buyers' clubs in England. In a personal interview, Dr. Evans explained that licensed drugs from Japan and England were sent to the States and that these drugs constituted part of the menu of the buyers' clubs in the United States. The fact that these drugs were not illegal or unlicensed in the UK could suggest that there was no need for buyers' clubs in England. In this line of argumentation, it is important to keep in mind that in the US there has never been a universal public health service as in England and individualism, as governmental rationality, is even more socially engrained in the US than in England. However, what can be more firmly argued is 'that alternative drug networks recall to an historian their nineteenth century forbears,

medical botanists and others, a self-consciously radical “fringe” in opposition to orthodox medical hegemony’ (Berridge 1994:485).

Evan’s statement was corroborated in another personal interview, in which the differences between the two countries in terms of the accessibility of treatments for opportunistic infections related to AIDS are evident:

> The AIDS treatment group in New York was campaigning to get hold of a particular drug that was used for treating cytomegalovirus (CMV) retinitis in particular, which was causing blindness in many many people including friends of mine, and the standard treatment drug, which was a drug that could be prescribed by any doctor in the National Health Service, it's a drug of choice, which approved efficacy wasn’t available in America, which was insane. So, my friend **X** came ... sort of come on a flight wobbling on sticks across to London to get prescriptions for St Marys to take back, a sack loaded with whatever that particular drug was, I can’t remember its name. Anyway, he was one of the earlier harbinger ones of what became the popular pharmacies, as in importing drugs. There was a recent film about it, a drug, say cartel is not the right the word, but a group in Texas Dallas, what was that called?
> Me: The Buyers’ Club
> The buyers’ club... well they call it buyers. The movie had that name, I think. But in fact, I think the first buyers’ club, really was the New York one, and Dr. Evans because he was registered as a doctor in London, actually technically in Edinburgh, but that's another story, would write prescriptions. I'd take them to the chemist shops in Camden town and my friends and I would pack up the parcels in my flat and send them off. (Jeremy. Age 70. Deal)

In any case, the arrival of the combination therapy along with a public health system that provided the drugs to all those who needed them would have made irrelevant the existence of buyers’ clubs. A participant in this study explained how he lived through the advent of antiretroviral combination therapy:

> The antiretrovirals came when I was just hanging on by a thread. I mean literally. It was pretty similar for Juan (his partner). I'm fortunate still to be alive. I mean it was a CMV in the eye, which has left me in such a state now. So, you know... I'm in treatment trips (sic), and I don't remember the exact day, but I went into those new drugs very early on, during trialling at the hospital. And it was actually remarkable, in fact. People talked about the Lazarus effect. I'm sure you heard this 'take your bed and walk' and it wasn't quite that dramatic, but it was… it was remarkable, gradually you became to notice, not so much feeling better, but actually you were in hospital less, that was very ... and then you began to feel more mobile, and then began to feel rather less fatigued. And then noticing the Kaposi's for which they've been doing all sorts of treatments, I had localised radiotherapy, I had injections into the lesions, it stopped coming, it stopped coming. The eye treatment, which at first had been a permanently implanted catheter which was now into direct injections into the eyeball. It's not very nice. Eventually, the immune system became, we don't need to do that. I mean this is remarkable (Harvey. Age 63. London).

This testimony highlights how being on antiretroviral drugs was literally a matter of life and death. Combinations of drugs were being trialled in hospitals around England and for many constituted coming back to life. From here the development of HIV drugs also included its promotion and marketing. But perhaps the most qualitative change in the history of buying drugs came with the emergence of the internet. The role of www.iwantprepnow.co.uk, a website that provides information on how to get PrEP online, was instrumental in the take-off of the consumption of generic versions of Truvada in England. Its co-founder Greg Owen stated in a personal interview, conducted in June 2017, that the website gets twenty thousand unique visitors a month and the top areas are London, Manchester, and Brighton. Owen estimates that the number of people buying generic Truvada through the website is between six and eight thousand. Owen explained how iwantprepnow.co.uk was set up:

> My friend Y who I met at an ACT UP meeting and who is quite, erm, really cute, he was on PrEP, he got it from New York without any social security number, prescription for free. […] As he was coming back, he meant to see his clinic and he said he was going to be out of the country for a while and they were like oh, ok […] and they loaded him up with six months of PrEP, they gave it to him to take on because they knew he definitely was at risk. As he was going to the end of his PrEP, there was knowledge that you can take four pills per week and have the same amount of protection or you can do 'on demand' like IPERGAY…he was starting to go very low so I called him up, 'are you going to try to figure any way'…we were both negative so we were trying to help each other out with how to get PrEP, so we wanted to do some research anyway for ourselves, for him and for him […]. I went to a HEP C meeting and they were talking about importing generic Harvoni for a cure, sure we can do this. Then I called a person, a friend, a very good friend who works in a sexual health clinic and I was like, 'we are thinking that we can get generic PrEP and we can import it and can you put me in the right direction, advice on where…' and he was like, 'come in tomorrow'. This person is very hard to get an appointment with… 'come in tomorrow at 3 o'clock', and I was like, 'really?'. And he said, 'yeah, bring Y with you'. And this friend who works in a sexual health clinic and who'll remain nameless said, 'ok, here's the thing, we have patients who we get PrEP from three online pharmacies, we have the name of the pharmacies, we have the name of the generic Truvada and we have anonymised TDM (therapeutic drug monitoring), the results', […] and I was fucking clueless and I was like, 'can we do this?' 'Yes, you can, and you NEED to do this'. (Greg Owen. Age 36. London)

This testimony encapsulates some of the tenets of biomedicalization theory such as the proactive role in health prevention. But most importantly, it points to some of the elements that will conform the assemblage of the new model of HIV prevention in England, such as the alliance between patients/activists and clinician activists. This is however, a very different story from Jeremy's, at least in relation to HIV. The testimony also refers to Harvoni, which is an antiviral drug for the treatment of Hep C, is well tolerated by patients, and has a very high rate of success for cure. Other treatments for Hep C were not as efficient and patients were not able

to tolerate treatment as well as with Harvoni. Harvoni, like Truvada, is a drug patented by Gilead laboratories and initially had an extremely expensive price, so many people, including health systems, could not afford to buy it. This testimony illustrates how drugs, and information about drugs, move back and forth across the Atlantic, and life and health is still at stake but in a radically different level. But what was the historical development that made the commodification of HIV prevention possible? The following section provides a historical account looking at the process of increasing commodification of health services in England.

Reorganisation of the NHS: from public to (increasingly) private

Enacted by the Labour Party, the National Health Act (1946) became effective in 1948 with the establishment of the NHS. The act aimed to provide a 'comprehensive health service in England and Wales designed to secure improvement in the physical and mental health of the people of England and Wales and the prevention, diagnosis and treatment of illness […]' (Great Britain 1946). Thanks to this law, people could have access to healthcare free at the point of delivery, regardless of their ability to pay. The access to health services was granted on the basis of need, which was evaluated by medical professionals. It has been stated that 'the vision informing the design of the NHS' was one that equated technocratic rationality with social justice' (Klein 2010:282). The idea that the state had some role to play in guaranteeing a certain level of healthcare and social security had been building since the nineteenth century. For example, with the National Insurance Act (1911) the government committed itself to paying a part of the health insurance for industrial workers. But it was the National Health Act (1946) that contributed to setting out the idea that the State had a fundamental role to play in caring for the health of its citizens.

It is necessary to state that right from the outset there was opposition to a free NHS. This opposition came from 'doctors, sections of the Labour Cabinet and also from the

Conservative Party' (Berridge 1999:15). The opposition to a nationalised NHS from the Labour Cabinet was led by Herbert Morrison, a statesman who believed that 'the move from a rate- to a tax-based system would lead to an increase in expenditure'(Ibid.). Notwithstanding opposition, the NHS has been able to maintain its 'free at delivery' service even though some critics have pointed out its chronic under-funding, 'particularly under Conservative stewardship' (Gorsky 2008:437). Reorganisation of the NHS has been ongoing, and the privatisation of its services began in the 1980s. Thus, the broad postwar consensus that supported the development of the NHS and the welfare state generally began to unravel with the rise of the new right under the Thatcher government in the 1980s. One of the first steps taken was to apply a business approach to the management of the NHS. Thus, managerialism became the strategy to improve the NHS's efficiency by relegating doctors from directive positions in hospitals. The Griffiths report (Pollock 2004) marked the origin of this shift, in which businessmen from different backgrounds were assigned managerial positions. It represented 'a direct challenge to the style in which the NHS has been run since its foundation' that changed 'the emphasis from the mobilisation of consent to the management of conflict, from committee work to entrepreneurship' (Klein 1985:48).

However, the intensification of this process has been gradual, and it needs to be framed in the context of the implementation and development of neoliberal doctrines that culminated with the Health and Social Care Act (2012). If the original Act of 1946 set out the idea that the government was responsible for the care of people's health, the 2012 Act reflects the neoliberal challenge to state welfarism with the creation and development of markets in multiple areas of healthcare provision. The 2012 Act gave the Secretary of State legal powers to create a market; in fact, the *British Medical Journal* wrote that 'a third of the contracts awarded to health providers went to the private sector a year after the act was passed' (BMJ 2014, 349). This reflects the idea that the provision of healthcare services can be understood in quasi-market

terms (Allen et al. 2017), and stresses further the notion of the patient as a consumer with choices. The latter is clear in section 75 of the Act, entitled 'Requirements as to procurement, patient choices and competition', in which the privatisation of the NHS was justified in terms of providing greater consumer choice (England 2012:99).

The case of PrEP provides an example of the confusion/contradictions resulting from the transition to a market-based health service. The 2012 Act failed, for example, to make clear who was ultimately responsible for people's health services. This lack of precision was exposed in the *National AIDS Trust v NHS Service Commissioning Board*, the court case that sought to determine who was responsible for commissioning PrEP in England. It was in this scenario of uncertainty that PrEP promotion and PrEP activism emerged in England, and it is in this scenario that the PrEP activist paradox developed. This activist paradox is based on the use of neoliberal language and the creation of a grey market around PrEP within a very regulated pharmaceutical market in England (Kazzazi et al. 2017). This paradox ultimately has to be credited, at least in part, with the drop in HIV infection.

From patients to consumers in the context of choice

The reconfiguration of patients as consumers also plays a role in the increasing commodification of health services. This reconfiguration needs to be understood as a process of neoliberal governmentality, in which the state, by releasing information, expects the population to act in a way that is beneficial to the individual while it achieves the goals of the state regarding matters of public health. The role of choice in this neoliberal governmentality process is key to understanding the reconfiguration of patients as consumers.

It is important to point out that there is a history of choices prior to the development of neoliberal policies that were not completely linked to individual rights. In fact, 'from the early 1960s onwards, the concept of "consumerism" within the NHS was organised around the

notion of provision that was seen to be collective or collectivist in the sense that it implied costs and benefits, rights and responsibilities, shared among all citizens, rather than individual choices'(O'Hara 2013:293) In this sense, 'consumerism', usually linked to the idea of individual rights, 'can be conceptualised in many ways, including as a social movement, a way of life or an ideology' (Ibid.). Therefore, the history of choices and consumerism in the realm of health care is characterised by its shifting meaning and it is parallel to the history of the reconfiguration of patients as consumers. In this sense, it is been argued 'that patient groups were central to the formation of patient-consumer, but as health consumerism was taken on by the state, they lost control of this figure' (Mold 2010:505).

The shift towards a neoliberal understanding of patient consumerism was strongly reflected in policy documents from the end of the 1980s to the beginning of 1990s (Mold and Berridge 2010:102). Originally this reconfiguration was meant to make the patient more responsible for his or her health through informed choices, but the way in which it was understood as giving rights to the patient was 'defined in a negative sense, through reduction of the power of some health care providers rather than through a positive desire to involve such "consumers" in the running of health services' (Berridge 1999:57). The language of such policies was/is one of choice and rights, but in practice the state retains control of the services themselves. The individual is responsible for making the right choices, but the choices available are limited to those dictated by professionals. At the same time, regardless of the neoliberal rhetoric of informed choice, complete privatisation was rejected, since there was a fear that consumers' choices in terms of treatment would greatly increase health care spending (Klein 1995). Gay men had been part of this shift from patients to consumers of sexual health since the 1970s, the sexual health clinic being a paradigmatic example of the reconfiguration of patients as service users and consumers (Pryce 2002). Moreover, part of the implementation

of PrEP in England is a collective version of this 1990s consumer power, in which 'patients' aligned with charities have exercised their power through legal procedures.

Choice continued to be central to the government's strategy for the NHS in the 2000s. As stated in a guidance document released by the Department of Health in 2003: 'Choice is central to the Government's vision for the NHS. Greater choice for all patients will help ensure all patients experience an NHS that is centered on their needs' (Department of Health 2003:3). A decade later, section 75 of the Social and Health Care Act (2012) again stressed the role of the government in promoting patients' choice, stating that 'regulations may impose requirements to "protect and promote the right of patients to make choices with respect to treatment or other health care services provided for the purposes of the NHS' (England 2012:99). In conclusion, the history of the reconfiguration of patients as consumers/users of health services can be contextualised within a history of development of choice policies. Gay men have been part of this reconfiguration, which has been intensified, at least at a policy level, within the last two decades.

PrEP users, consumers or patients?

But, how did these policies shape the practices of PrEP users in England? To better understand the subjective experience of PrEP users in the history of the reconfiguration of patients as users or consumers, in this study I asked PrEP users to identify with one of the following categories in relation to PrEP practices, including clinical services: patient, user or consumer. All the interviewees refused to identify themselves as patients or consumers. The excerpts below show some of the arguments against the identification of PrEP patients or PrEP consumers:

> I've never been keen on the word patient because it always implies something… kind of that you are poorly and usually when I'm using Dean Street, I'm not poorly, so I don't think I identify as that. I don't think so. Surely not consumer, I've got

> real issues with the notion of consumer, I don't like to use that word. So nearest would probably be service user. (Warren. Age 54. Southeast London)

> You need to be careful if you start referring to people as clients. Clients is a professional term, this is not a professional thing, this is a medical service, this is a preventive medical service, this is not, I'm going to see the plastic surgeon to get my nose done, that's choice, that's purely for yourself, that choice, […] but for PrEP I think you are making the choice, you are making the decision to safeguard yourself and others, so, and it's medical. (Jim. Age 34. Brighton)

If the first testimony exemplifies the negative perception of the term consumer, the second highlights how choice is a key element to understand the stigmatisation of 'health consumerism'. If decisions are supported by community values, then they seem more legitimate than those taken for individualistic reasons. Therefore, the lack of identification as sexual health consumers for some participants in the study seems contradictory to the thesis that defends the commodification of PrEP and the view of PrEP as a commodity. As I have argued elsewhere, the commodification of PrEP was not seen as a deterrent, but as a way to remove barriers to PrEP access (Martinez-Lacabe 2019). However, to disregard the commodified aspects of PrEP access would be to trivialise the influence of consumer culture on gay men's lives and its power in creating lifestyles and providing identities (Haslop et al. 1998). In the interviews, the theme of choice emerged as something important for the agency of the interviewees and in relation to the act of buying PrEP:

> Well, it's my choice…so, I don't have someone else to pay for it. And, I think it would be a great cause… it supports our community, and everyone benefits from it. (Christian. Age 31. Brighton)

> I think that what taking PrEP is […] it sends a very strong message that, we can have choices, and we can decide, and we can be fine, and we are serious about protecting ourselves and other people as well. (Edward. Age 38. Brighton)

As can be inferred from these testimonies, the concept of choice is embedded in discourses related to personal agency and personal responsibility, but also in discourses linked to solidarity. This appeal to community and solidarity in turn relates to a form of activism that is fundamentally shaped by the action of buying PrEP online, which represents an unorthodox but increasingly common way of accessing drugs. In this sense, creating a PrEP sourcing platform by means of a PrEP grey market or buyers' clubs was not a novelty in the history of HIV and AIDS.

Getting pre-exposure prophylaxis: becoming active agents of biomedicalisation

Perspectives on biomedicalisation acknowledge that because of the increasing role of biomedicine in people's lives, biomedicalisation is producing 'new forms of agency, empowerment, confusion, resistance, responsibility, docility, subjugation, citizenship, subjectivity, and morality' (Clarke et al. 2003:185). This section explores the extent of human agency by looking at testimonies about the sourcing of PrEP in England, and how these experiences constitute subjectification mechanisms that produced forms of self-understanding in relation to HIV prevention. All the actions described by participants in the study – getting PrEP on a grey market without medical prescription, clinic hopping, guinea pigging and enrolling in clinical trials – require a level of agency and will that distances these men from the idea of the passive medicalised gay man, while bringing them closer to the active patient model proposed by Armstrong (1995). The following testimony illustrates the practice of clinic hopping and exposes the conflicts resulting from it:

> I realised that I wanted to be on PrEP and what I started doing, me and a few of my friends, was clinic hopping. You may've heard of this. So, every month, I would go to a different clinic and I would say: 'Last night I had unprotected sex with someone, they came inside me, and I don't know what their status was', and they would go: 'Here is your PEP : Truvada and Raltegravir. Take one of these a day,

> take one of these twice a day'. 'Thank you'. I would go home, keep the Raltegravir, still have it and I would take the Truvada as PrEP. I was doing that for maybe six months and then different clinics each month. I went to X clinic here, about month six, and I went: 'I had sex last night with someone unprotected I need PEP' and the nurse said: 'Are you using PEP as PrEP?' And very transparent, never lied, I went 'Yes, I am'. She said: 'Do you realise that every time you do this, it costs us 400 pounds?' And I said, 'Do you realise that I can contract HIV because the NHS won't provide me with the medication you should, and my health is gonna go first. As a gay man I'm not using your skills, I'm not using anything that straight people would use, I am not having cost for NHS for childbirth, I pay my taxes and I don't feel guilty at all about having taken monthly 400 pounds of the NHS for HIV medication [...] until Truvada becomes available on the NHS I am going to look after my health.' And that went for a little while. (Carlo. Age 39. East Croydon)

Clinic hopping demonstrates a proactive disposition among those who engage in the practice. In the previous testimony there is a process of negotiation about the legitimacy of getting the medication in an illicit way, clearly triggered by the interviewee's perception of inequalities in the distribution of health care resources between different populations. This negotiation works as an intersubjective process to validate rights claims (Arvanitis and Karampatzos 2013) while giving rise to new forms of ‘therapeutic/pharmaceutical citizenship' (Nguyen 2007; Ecks 2005). This pharmaceutical citizenship is not only enabled through discourses of rights, but also through an ‘entrepreneur of himself’ mentality (Foucault 2008) characterised by 'the idea and practice of responsibilization – forcing the subject to become a responsible self-investor and self-provider' (Brown 2015:84). Thus, the biomedicalisation thesis argues that 'biomedical governmentality [...] often relies on a neo-liberal consumer discourse that promotes being "proactive" and "taking charge" of one's health' (Clarke et al. 2003, 181).

Risk and personal responsibility discourses and their role in the biomedicalisation of HIV Prevention

The aim of this section is to introduce the argument that in the frame of the AIDS/HIV epidemic in England, gay men have been historically objectified as an at-risk group through HIV prevention discourses along with calls to personal responsibility. This has contributed to the creation of the non-positive antiretroviral gay body figure. Thus, in the early days of the AIDS crisis, the idea emerged that gay men have a moral responsibility not to acquire and/or transmit HIV. Parallel to this idea, there was a transformation of the concept of risk, which was increasingly identified with danger rather than with probability. Over the course of the epidemic, the goal has become to find zero-risk strategies, or at least keep risk to a minimum to avoid such danger. This is the rationality of PrEP discourses, and the logic of the non-positive antiretroviral body, who, by eliminating any possibility of risk through a compendium of biomedical and behavioral strategies, raises himself as a bearer of moral responsibility.

Thus, from the very beginning of the epidemic, HIV prevention discourses have classified people in different groups of risk based on epidemiological statistics. Due to the higher incidence of HIV infections, gay men have historically been ascribed with the highest levels of risk for contracting HIV. During the first two decades of the epidemic, talking about high-risk groups or groups with high-risk behaviour instead of high-risk practices was common language. This contributed to the stigmatisation of those who engaged in high risk practices and helped to perpetuate the idea that HIV is mostly a gay issue. As a result of these historical developments, being gay still equates to being at risk of contracting HIV. An interviewee for this project talks about the links between prevention discourses and being gay:

> I think that it's pretty disconnected between what was the risk of my activity in that sense of what I was doing, which actually would have very minimal risk at all, and the identification of being gay which is you are at high risk of HIV. So that for telling people that'd be no you get labelled as being at risk of HIV, so you know

> that and you recognise that, as you carried it with you, but also you don't identify with that in a way, or you are kind of co-opting this too. So, and never really knowing where you sat on that, in a way. It might be that time I did have sex and we had, you know, kind of oral sex, maybe that had put me at risk, or maybe I do have HIV and just not really knowing, but you are always told you are high risk. Naturally. Cause you are gay. (Leo. Age 40. East London)

For the interviewee, the association between being gay and being considered at high risk of contracting HIV is obviously an effect of HIV prevention discourses, which sometimes have ignored the competency of gay men who try to adopt preventive measures in different ways. This fact has been criticised in the following way: 'Although gay men quickly and sensibly deduced that one would be at less risk of HIV infection by going top or by receiving semen on the body rather than in, HIV prevention declined to condone its community's own risk-management strategies' (Russel 2006:148). These practices, which entail choosing partners according to their HIV status, coitus interruptus, or sero-positioning, were not exempt from risk, but were shown to reduce risk (Ibid.). For example, the practice of sero-positioning involves taking on a specific sexual role depending on HIV status. So, being the active partner (giver or top) involves less risk than being the passive partner (taker or bottom) since the surface of the interior of the anus is greater than that of the penis, and the risk of tearing in the anus during sex is greater since the inner membrane of the anus is more delicate than the skin of the penis. And this is an example of how perceptions of risk and risk prevention have in turn shaped sexual roles and identities.

Sociologists have identified the late twentieth and early twenty-first century industrialised West as 'risk societies' in which the development of risk theories, such as risk assessment and risk communication, have engendered well-stablished industries giving the concept of risk a predominant place in our world and a new role in the way we understand everyday life (Lupton 1993:425). In other words, in the contemporary era the way citizens

experience life is intimately linked to the way we understand risk. In the case of many gay men in England, their sexual lives have been heavily shaped by HIV prevention discourses on risk management since the 1980s. These discourses have changed over time in parallel with scientific discoveries on HIV prevention. The following excerpt was taken from the Lesbian and Gay National Survey archives and it introduces the testimony of a gay man who was affected by the AIDS crisis. It is a clear illustration of the way someone navigated risks prior to the emergence of antiretroviral drugs for prevention:

> As far as I recall, I first heard about AIDS in the very early 80s. At that time, I was in a monogamous relationship and I did not believe it affected me. When the relationship broke up, in 1984, I carefully considered whether to change my social lifestyle but considered the disease so rare at that time that the hassle of using condoms was not justified. In 1986, I entered into another monogamous relationship and we consciously decided not to practice safer sex as we believed that we were both infection-free. The relationship broke up in early 1990 and I immediately adopted safer sex practices since I believe that the much higher risk factor due to spread of disease necessitated that. In late 1990 I began another monogamous relationship in which we practice safer sex, although I know my partner would prefer not to as we have both been tested fairly recently and found to be HIV negative. (NLGS respondent 3 / 376 D. Born in 1948 in mid-Wales, living in London.)

What becomes clear from this testimony is the way in which the strategies of risk management are informed by this person's perception of the risk, which invariably changes as the epidemic advances and his personal situation evolves. Thus from 1984 to 1986, he decided not to adopt safe sex practices, even when he was not in a monogamous relationship, since he considered that the risk was not high at the time. This contrasts with his decision four years later to practice safe sex, even with his partner after both had tested negative for HIV. This testimony corroborates the theory that the concept of risk has transitioned from being something neutral,

'referring to probability, or the mathematical likelihood of an event occurring that not necessarily involves a negative outcome,' (Lupton 1993:425) to being something negative, to signify almost always an unwanted outcome. Today, risk equals danger and 'high risk means a lot of danger' (Douglas 2003:24). This is particularly true in public health discourses where the use of risk as a synonym for danger is an ongoing practice (Lupton 1993). For example, the labelling of gay men as being at 'high risk' conveys the idea that they are in danger of contracting HIV. As an unwanted collateral effect, gay men, who traditionally have been considered 'at-risk' through epidemiology discourses, have become morally responsible for their own risk.

As mentioned above, the way we assess, measure, and control risk becomes the way we come to understand ourselves in terms of personal and moral responsibility. This is fundamental to PrEP practices, since PrEP is a prevention intervention based on discourses of risk and responsibility. The following excerpt illustrates the way in which a PrEP user understands that responsibility and chemoprophylaxis are concomitant:

> Being a PrEP user comes with some levels of responsibility and that responsibility includes making sure it is not to damage my body, making sure that it is not enhancing any other aspect of ill health such as increased vulnerability to syphilis or anything else. So, for me taking PrEP gives me another layer of self-care, and I think is incredibly responsible thing for me to do, that's a tool that's there and why wouldn't I use it if it's there. So, for me it feels like the ultimate act of responsibility. (Logan. Age 49. London)

From this testimony it can be inferred that the language surrounding PrEP is concerned with the concept of responsibility and the management of risk. The extra 'layer of self-care' implies, in a Foucauldian sense, the governing of the self through the management of risk, which at the same time gives rise to new ways of understanding the self. This is a process of gay governmentality via a biomedical form of HIV prevention. It is related to the deontological

aspect of pharmaco-regulatory practices, with the forms of subjectification, in this case with the production of the responsible subject.

But, what kind of terminology has shaped risk and personal responsibility perceptions? In HIV prevention discourses, PrEP has been described as a "strategy", "prevention intervention", "prevention tool", "game changer" and "key choice", among other terms.[4] This nomenclature relates to two already classic cultural paradigms that have been constantly deployed in the context of HIV prevention and treatment. One is the personal responsibility paradigm and the other is the military metaphor that refers to different features and circumstances around HIV/ AIDS. Terms such as "strategy" or "prevention intervention" are part of the military imagery that, in the words of Susan Sontag, is 'far from being inconsequential' (Sontag 1989:180). For instance, the use of the term "prevention intervention" in an HIV context legitimises the administration of antiretroviral drugs in a body in which there is no presence of HIV. Military terminology, in combination with health and safety terminologies, contributes to the construction of the idea of risk, which at the same time justifies intervention. In this respect, it is useful to understand the difference between hazards and risks, the idea that 'hazards are real, and risks are cultural' (Fox 1999:17). In the HIV context, this would mean that HIV is a hazard to bodies, but the risk of contracting it is defined through variable medical parameters, such as detectable/undetectable viral load or "risk practices", and it is therefore possible to state that risk is culturally constructed and obeys someone´s logic. Nevertheless, this constructionist approach to risk has been criticised for: '(i) challenging the legitimacy of risk (ii) undertheorising the relational, the emotive and the moral dimension, and (iii) totalising social space by ignoring the ways in which individuals construct themselves as moral subjects by contesting risk techniques' (Roth 2010:48).

[4] http://www.prepwatch.org

Moreover, the constructional approach to risk has also been interpreted as a technique, 'a way of governing conduct of individuals, collectivities and populations' (Dean 1999:206). In this sense, acknowledging that risk is a powerful and sophisticated technique of social control helps to understand why some individuals, collectivities or even populations engage in self-governing practices with the goal of avoiding risks. PrEP facilitates zero-risk (bio)governmentalities and it is in this sense that the link between biomedicalisation and (bio) governmentality is easier to understand. Thus, gay men who buy online PrEP may or may not do a self-evaluation of their risk practices and take PrEP to enjoy condomless sex, which is a legitimate reason in itself. As will be discussed in chapter six when looking at practices of freedoms and PrEP, many gay men are not taking PrEP from a merely HIV prevention perspective. This mean that these men would probably continue being HIV negative even without taking PrEP. This presents an ethical conundrum. On one hand it is important to accept that gay men have the necessary agency to take decisions in relation to their sexual health. On the other hand, if PrEP is being used for purposes other than HIV prevention, should this not made be clear? Some activists and academics have pointed to this different use of PrEP as something positive, but the original reason for the implementation of PrEP was to be used in those men at high risk of contracting HIV. The question is the following: Can the success in the decrease in HIV infections justify the fact that there are men who are taking PrEP without needing it from the point of view of HIV prevention? The answer lies in the relation between the alignment of the gay men's desires and public health goals.

Returning to the military imagery, its language can be very effective to produce the call to action. This call to action was highly present in media and in public health campaigns. Gus Cairns, co-chair of the PROUD Trial, explains in an article titled 'D-Day for the Pill of HIV' that 'if you give PrEP to the right, motivated and prepared, gay men, they will take PrEP (both

daily and intermittently) and it will work.'[5] This line exemplifies the divide that PrEP creates between those gay men who are 'motivated and prepared' – the *right* ones – and those who are not. Thus, this statement shows not only the intersections of the neoliberal rationale and self-governance practices advocated by some health promoters, but also the mechanics of the stigmatisation processes through the creation of divisions. This is problematic not only because it contributes to the stigmatisation of those who do not want to be on PrEP, but also to the stigmatisation of those who cannot have access to PrEP for various reasons.

Furthermore, a recent UK-based study explores how newsprint played an important role in delivering a narrative that produced "responsible" and "irresponsible" imagined PrEP users (Young et al. 2020). This divide, which might be useful in terms of knowing who the right candidates are to embrace a biomedical intervention or as a criterion for enrolling in a clinical trial, falls into the category of the public health imperative. This imperative draws on the idea that people, in this case gay men, must engage in public health interventions for the sake of the global population. This type of public health imperative may sometimes clash with individual rights and, therefore, distinctions need to be made to resolve this tension. The following testimony from the director of the PROUD study addresses those distinctions when commenting on the results of the trial:

> For gay men who are not having anal sex, I guess the results don't mean anything at all. And for gay men who only have anal sex with a condom, again, this doesn't really add anything because the condoms are still the best way to reduce the risk across the board for sexually transmitted infections. But for gay men who can't use a condom correctly and consistently every time they have anal sex, then this is a fantastic new prevention tool, that will reduce their risk of HIV (Sheena McCormak)

[5] http://www.huffingtonpost.co.uk/gus-cairns/the-pill-for-hiv-has-just_b_6101584.html

From this testimony it can be concluded that PrEP should be directed to a very specific sector of the population. On a similar note and as is well explained on the PrEPster website: 'the media may report an innovation (such as PrEP) as if it is a silver bullet, a simple solution that on its own will end the HIV epidemic' (Prester 2020). Although not completely similar to the silver bullet concept, it is true that at least during the first steps in the promotion of PrEP, the PrEP assemblage conveyed that idea by saying that with PrEP we had all the necessary tools to end the epidemic. From an ethical point of view, this is questionable since this message about ending the epidemic can be interpreted by many as a call to action to engage in PrEP practices. With all of the above exposed, it can be concluded that the language of risk, often linked to the concept of personal responsibility, has had an important role in the biomedicalisation of HIV prevention in England.

Surveillance: Molecular gaze, screening, viral loads and therapeutic drug monitoring

The connection between risk and surveillance is a key feature in the processes of medicalization, which place groups characterised with certain vulnerabilities, such as gay men, under medical surveillance. In the words of Mary Douglas, 'their state of being "at risk" justifies bringing them under social control' (Douglas 1986:57). This idea of being at risk and bringing people under control is still dominant within biomedicalization perspectives, but what is new is the idea that surveillance methods can now include the molecular gaze. This molecular gaze has been constructed thanks to the sophistication of biomolecular technologies. In the realm of HIV prevention and treatment, these biomolecular technologies have a key role in the surveillance of gay men.

HIV testing has been the main technique for the surveillance of the gay population. In England, testing proved to be very challenging at the beginning of the epidemic, since there was no treatment available and some gay men did not trust the guarantee of confidentiality. As

inferred from several testimonies in the Lesbian and Gay National Survey, getting a positive HTLVIII test would prevent, or at least seriously hinder, access to jobs, insurance, and mortgages. The following testimonies extracted from the survey archives illustrate this situation:

> Probably, the AIDS fear is more pervasive because it covers not only areas of personal lifestyle and health but also other things, for example I hope to give up my job this year in order to study full time and sell my house in order to fund this but will I ever get back to the superannuation scheme and will I ever be able to buy another house without taking an HTLV3 test? And that poses a whole set of questions about taking the test at all what that means in terms of invasion of privacy, opening myself up to the possibility of discrimination on account of homosexuality. (NLGS respondent 166. 1986)

> I do think it is important to know my HIV status. I am aware of the very large number of people who will not take the test because they are worried about the legal consequences – insurance, mortgages, jobs. I think that providing protection from discrimination against those who have tested positive, and even against those who have been tested and are negative, is probably the best thing that could be done now to reduce the spread of the disease. (NLGS respondent 375. 1991)

These testimonies contrast with the current mentality that many gay men have regarding testing. Although there is still some resistance to testing, for many gay men today testing is an assumed part of their life, and for PrEP users, the non-positive antiretroviral gay bodies, testing is an intrinsic part of their lives. The following testimony illustrates the process of negotiation between two partners on taking PrEP and the role of testing within PrEP practices. I asked the interviewee when the first time was he heard about PrEP:

> First time, probably here in Brighton. I went to get tested here, cause someone told me: oh, I've got an STI and you should go and get tested. And this guy at the hospital, this sexual health clinic he was quite awful, I think, cause he's like, 'you

> have sex without condoms, you live in Brighton and it is very high risk.' He really scared me, I think he did that on purpose, cause I thought: oh my god, where I have moved to, this city is awful. And so that's how I heard about it, but I didn't want to take it (the PrEP) and then I heard about then probably last year, March, cause I'm with my partner now almost two years, and he was on PrEP before he met me, but I didn't know. But when we met, I think he stopped taking it, or like a few months after but I remember to get tested every three months and it was like: why are you doing that? Cause we are now in a relationship, why do you have to get tested all the time, is a bit weird, are you doing lots of stuff with other people, and he said no, no, it's just what I do. But then, a few months after it came up again, I don't know how but we talked about PrEP and then he said, I took it before I met you and then he said, 'that's why I get it tested just to see how my body's reacting to PrEP.' But now, it makes sense, but you should have told me cause you fucking scared me cause I thought he is cheating on me. (Christian. Age 31. Brighton)

This testimony echoes a theme of some of my other interview testimonies, which is the difficulty among partners of talking about PrEP. In this sense, it is necessary to acknowledge the emergence of another dimension of surveillance, an intrapersonal surveillance between partners due to PrEP practices. This type of surveillance covers the realm of individuals, but testing has traditionally been to monitor populations as well.

As mentioned above, one of the characteristics of the biomedicalization of HIV prevention is the advance of biomolecular techniques, out of which the *polymerase chain reaction* stands as one of the most important. This allows biologists to measure the level of virus, and how infectious a person who lives with the virus is. Thus, a person with an (HIV) undetectable viral load is a person who cannot transmit HIV, and a person with a high viral load can pass on the virus more easily. Public health programmes not only have the objective of achieving undetectable viral loads in individuals, but they also aim to get populations' viral loads to be undetectable. For example, Brighton became the first city in England to become part of the international Fast-Track Cities programme, the targets of which include 90% of

people living with HIV (PLHIV) knowing their HIV status, 90% of PLHIV who know their HIV-positive status being on antiretroviral therapy (ART), and 90% of PLHIV on ART achieving viral suppression (Martin Fisher Foundation 2017:1). These three goals require a biomolecular approach since it is necessary to test people who ignore their HIV status, to put the antiretroviral drugs in the bodies of those who need treatment, and to ensure that the viral load of those on treatment becomes undetectable and therefore non-transmittable. In the UK, the CD4 Surveillance Scheme monitors the T-lymphocyte counts performed by laboratories in England and Wales. Data is used to calculate late HIV diagnoses, access to HIV care, and the clinical outcomes of those living with HIV (Public Health England 2008). It is clear, then, that surveillance is still a tool for the governance of populations through a molecular gaze.

In the case of PrEP, molecular surveillance is a key way in which health professionals can monitor adherence to the treatment. One of the limitations of the PROUD study was the lack of data regarding adherence to PrEP. A way of solving this was the collection of blood samples. As stated in the report, 'the measured drug concentrations validated the reports of participants who said they were taking the drug, by contrast with placebo-controlled trials' (McCormack et al. 2016:58). The fact that this trial relied on blood tests to measure adherence to the drug and overlooked participant's questionnaires was acknowledged by Tim Dean's reflection on the new possibilities and means of researching medical sexualities:

> What I find intriguing about chemoprophylaxis is that the reliance on self-reports of adherence may be qualified by more objective measurements of drug levels in plasma. Sexual surveillance now can bypass subjectivity altogether by going directly inside the body to elicit information. In this way, the new technologies make visible a chasm between what gay men are willing to tell medical or scientific authorities and what they are actually doing in their everyday lives (Dean 2015:231)

This biomolecular surveillance partially solves the problem of monitoring sexual practices in the context of sexual health or genitourinary (GUM) clinics. How much information a patient might reveal to sexual health providers is no longer an issue if the patient agrees to be monitored through levels of drug-in-blood. What is surveilled now is the level of drug-in-blood that protects the patient/consumer from HIV infection. As long as there is enough drug in the blood to be measured, it is not necessary to know what kind of sexual practices the patient/consumer engages with. It is no longer necessary to ask the monitored patient/consumer to disclose the number and/or nationalities of their partners, their role as 'giver' or 'taker' in their sexual practices, their use of condoms in those practices, or whether or not the practices are oral or anal. These kinds of questions are becoming more and more irrelevant for the monitoring of antiretroviral gay bodies.

PrEP, the transformation of bodies and the production of new techno-scientific subjectivities

Relevant to the transformations of bodies and the emergence of new techno-scientific subjectivities is Nikolas Rose's concept of *technologies of optimisation*. These kinds of technologies do not only seek to heal the body once the pathogen agent is present in the system, but also look 'to control the vital processes of the body and mind' (Rose 2007a:15). Technologies of optimisation are embedded within a new biomedical epistemological frame that is the outcome of current forms of understanding the human body. This epistemological frame features a displacement from the molar level to the molecular level, from the organs to the cells, from what can be detected by the naked eye in a microscope to what remained invisible in previous decades (Ibid., p.14). This shift has been achieved thanks to new techniques of visualisation that 'operate through digital simulation' and a combination of techniques for the manipulation of DNA including the use of enzymes to cut DNA, or the reproduction of DNA for analysis purposes (Rose 2007a). Technologies of optimisation work

at the molecular level to optimise human biology, but most importantly, they try to shape 'the vital future by action in the vital present' (Ibid., p.18). It is within this molecular context that Rose develops the concepts of *susceptibility* and *enhancement*.

Rose describes the susceptibility dimension as 'the problems raised by attempts to identify and treat persons in the present in relation to ills that they are predicted to suffer in the future' (Ibid.). Rose elaborates the concept of susceptibility in connection with the development of new technologies, such as *polymerase chain reactions* (PCR), which amplifies strands of DNA in order to diagnose hereditary diseases and, as mentioned before, it is used for the diagnosis and measure of HIV levels in blood. This principle of susceptibility, Rose explains, 'is merely an extension of two other modes of thought that have a long story—that of predisposition and that of risk' (Ibid.). For example, specialists might look for a mutation in either the BRCA1 or BRCA2 gene to assess the risk a woman might have of developing breast cancer and her suitability for chemoprevention. However, although PrEP belongs to the era of the biomedicalisation, gay populations susceptible to being on PrEP have been targeted through analysis of risk practices and not via biomolecular methods such as blood tests or DNA analysis. Despite this, PrEP has the potential to transform or at least to enhance the abilities of the immune system through a molecular intervention and it is at this molecular level that bodies are transformed and become non-positive antiretroviral gay bodies.

The production of new technoscientific subjectivities is associated with some parts of the governmental dimension of PrEP, that will be further developed in chapter 5, where I analyze self-surveillance mechanisms through PrEP. For now, it is necessary to remember that if the medicalised subject has been traditionally understood as a passive subject, the bio-medicalised subject has an active role within the medicalisation of his body. In the case of PrEP, 'patients' voluntarily enroll in clinical trials, they assess their risk practices, they put a focus on health rather than on disease, they bring about new forms of understanding themselves

in their relationship with HIV and identify themselves with new technoscientific subjectivities. People taking PrEP identify themselves as *PrEPsters, PrEP warriors,* or *Truvada whores*, to name a few. This process of identification with those PrEP-related identities indicates the success of HIV prevention campaigners, such as the one delivered by I Want PrEP Now since 2016, in convincing people to adopt PrEP practices.

This differentiation of active and passive consumers/patients is important because it signifies a change in the way gay populations are governed in the HIV prevention realm – from being objects of medical government, to active subjects in their own governance. The following testimony illustrates the position of someone who is actively involved in a process of biomedicalisation of his sexuality. The question posed to the participant was to gauge his own thoughts and feelings of himself in relation to the act of self-administration of the drug- the subjective experience of it. I asked the participant to describe 'who he was' at the moment of taking his pill:

> So, when I'm taking the pill…. I'm somebody who's ….I guess ….I am trying to think the right words, I've taken my initiative, I'm importing this drug myself, I'm taking some kind of control, maybe being a bit smart, a bit clever, I looked up the data and I believed in this, you know, this drug thing and I'm taking it, and there's also a kind of element of I'm being a bit naughty, because there's still you know in the background the idea that actually I should still using condoms all the time and some of my friends are like oh yes I'm taking PrEP but also using condoms, and I am like oh ok. (Liam. Age 39. London)

This testimony sums up the traits of the new subjects of biomedicalisation. The fact that part of the participant's answer is related to the actions needed to buy the drug shows the role of 'taking initiative', 'importing', 'taking control', in his process of self-understanding. These are actions that reflect the biomedicalised subjectivity, not the traditional medicalised one. Therefore, the role of antiretroviral drugs in recent years both for prevention and treatment

have brought up forms of customised identities and new ways of understanding identities in relation to antiretroviral drugs.

The Diversification of Sources in the Production and Distribution of PrEP knowledge

> With newsletters and factfiles, with help centres and information offices, the medical and the gay worlds have created a system that ignores hierarchies of knowledge. Access is the key, to your diagnosis, to your prognosis, and – crucially – to your antibiosis or prophylaxis (Moore 1995:125).

The proliferation of different sources of information related to health and illness is a distinctive process of biomedicalised societies. Today, the general public has more access to medical information than ever in history and the internet has played a leading role in the production and distribution of health-related information. The traditional top-down, doctor-to-patient communication is being, if not replaced, at least complemented by new forms of knowledge distribution, among which the internet is the most important. Thus, online communities have emerged around an indefinite number of illnesses and conditions with the goal of exchanging information and personal experiences related to the conditions. In this sense, Facebook, with 1.8 billion active users, has become the new place for many in search of peer support groups.

From common conditions such as arthritis or cardiomyopathies to rare ones such as Lichen Sclerosis or Amyotrophic Lateral Sclerosis, people look to Facebook for information and support. The case of PrEP is unique since it focusses on a prevention strategy and not on an illness or a condition. *PrEP Facts: Rethinking HIV prevention and sex* is, with more than twenty thousand members, the largest and most active group on the web. The online group, founded in United States, has members from all around the word and has distributed information about PrEP since 2013. The group not only provides information, but also works as a peer support community in which members of the group use their own experiences to help

others.

Briggs and Hallin identified three models to analyse the communicability of different types of health-related information. By communicability they refer to the ways in which knowledge and information about health and medicine are supposed to be produced and distributed and who are 'the actors who play specific roles in this projected flow of information' (2010:122). The three models were (1) the Medical Authority Model in which there is a top-down transmission of knowledge, (2) The Patient-Consumer model 'which centers on active lay patient-consumers who seek medical information and use it to make choices about issues that affect their health and (3) the Public Sphere Model which 'centers around the citizen who will judge the actions and claims of public health authorities and biomedical professionals, and may, in some variants of the model, actively enter into the production and discussion of health related information' (Ibid.). A group like *PrEP Facts: Rethinking HIV prevention and sex* falls mostly within the Patient-Consumer model, featuring a high number of posts from people asking about diverse questions surrounding PrEP, including (1) medical, such as, for example, the managing of side effects derived from PrEP medication or ways to adhere to treatment, (2) ways to get PrEP, or (3) social issues around PrEP, such as how to deal with PrEP shaming or how to deal with PrEP related situations in gay dating apps.

The following interviewee explains the importance of *PrEP Facts: Rethinking HIV prevention and sex* in the process of negotiating the suitability of PrEP for him:

> The Facebook group was my main source of information, I was aware of IwantPrEPnow and I did look at that website. I was also aware of PrEPster and I used their website but, and they were great , both sites, specially about sourcing PrEP, you know, but what I really liked about the Facebook group was their dynamic and people asking questions, and also for me, being a mathematician and a musician I kind of have a sort of…. I like evidences, I like things just to stack up, to add up, to make sense and the people on, particularly Damon who is behind the whole Facebook group, they presented me information in a really clear way, of

> course they say is not a hundred percent, we know why, because there are these three cases, but when you look at that, if there are two hundred and fifty thousand people taking PrEP which probably are worldwide, the 3 people, obviously is sad for them, but statistically, is pretty insignificant. So, the Facebook group really convinced me of the wisdom of it. (Warren. Age 54. Southeast London)

The previous testimony illustrates the essence of patient-consumer model of biocommunicability where users share, gather and assess information to finally act in the way that is more convenient for their health. It is a clear process of active biomedicalization, distant from traditional understandings of the passive medicalised body.

The role of dating apps in the proliferation and diversification of medical knowledge needs also to be acknowledged. Gay dating apps like Grindr, Growlr or Scruff are used as online platforms where gay men can meet other men. Apart from the role of these apps in the commodification of gay sex, the platforms are used by sexual health promoters to advertise PrEP or testing of STIs. For example, it is possible to get tested for STIs at home by ordering a test kit online. These test kits are free, depending on the area and the age of the person who wants the kit. Thus, the website www.freetest.me offers free kits for HIV testing at home. They also offer the possibility of buying a home test kit for other STIs if the person is older than twenty-four. In the case of being over twenty-four, they advertise that it is still possible to get access to free and confidential screening in sexual health clinics.

Gay dating apps also offer a safe and friendly space for the exchange of information among users. These apps have been relevant for some of the interviewees in their PrEP related decision-making process. The following testimony illustrates this point:

> Yes, I know a couple of people who I was talking to in the dating apps and actually one of those I became very friendly with. As friends strictly platonic, which is interesting, (laughs) he'd been taking PrEP for a while so I was very keen to talk to him and find out about his experiences of it and one of the things I was curious

> about was what the side effects could be as well. So, even before i decided to take it i had spoken to him where he got it from, and interestingly when I started talking to him, my first assumption I made as soon as I knew he took PrEP was that his preference is to have unprotected sex and that's all he wants and that's what he does and I put him in a box with lots of (he pauses) And know I'm thinking of people doing that to me now. (Edward. Age 38. Brighton)

However, it is important to state that other interviewees have acknowledged that their decision-making process did not always involve getting information from online sources. The diversification of sources extends to friends and partners, and at least four of the interviewees for this project have acknowledged the existence of a process of negotiation among partners that involved the recompilation and analysis of data on PrEP.

Conclusion

This chapter has focused mainly on demonstrating how PrEP practices conform to or challenge theories of biomedicalisation and how this fact has facilitated the emergence of the figure of the non-positive antiretroviral gay body. As I have explained, those processes of biomedicalisation are characterised by techno-scientific advances in biomedicine and developments in digital technology, as well as neoliberal economics, globalisation and consumer cultures. As a result of this shift towards biomedicalisation, there is a predominant focus on biomolecular HIV prevention methods that distance themselves from previous behavioural prevention methods. The traditional, passive medicalised gay subject features now in an active role in his own biomedicalisation, a process made up of five key dimensions. The first is the commodification of sexual health through practices of PrEP. PrEP is an unparalleled example of how sexual health is understood as a commodity. Gay men not only enrol in clinical trials to have access to PrEP, but they also buy it online or even from dealers on the street. Understanding PrEP as a commodity means that that those who want to take the medicine do

so on their own initiative, which contrasts with the traditional criticism of medicalisation as an external imposition.

The second process of biomedicalisation in which PrEP is embedded relates to the development of risk theories and discourses of personal responsibility. These discourses have a strong impact on those who engage in PrEP practices and have become the lens through which many gay men view their sexuality. Ideas about risk are usually accompanied by discourses involving personal responsibility and morality. Moreover, discourses about HIV prevention usually emphasise the idea that it is the individual who is ultimately responsible for their sexual health. This argument acts as a driver of the processes of biomedicalisation. The third dimension is concerned with new surveillance methods and the biomolecular gaze, with concepts like 'viral load' or the 'therapeutic monitoring' of the drug. Scientific advances have made it possible to omit subjectivity in the field of sexual health research. It is no longer necessary to rely on personal testimonies to know about someone's adherence to PrEP because adherence can be determined through blood analysis. The fourth dimension is related to the modification of bodies and the production of new technoscientific subjectivities. PrEP penetrates the body orally and changes it at the molecular level by optimizing the immune system's response to an HIV infection. This desired effect is connected to the creation of new subjectivities and new ways to produce the self with regard to HIV prevention. Moreover, there is a process of identification with some labels like *PrEPsters*, *Truvada Whore* or *PrEP hero* created by HIV knowledge producers. Finally, the diversification in the production and distribution of medical knowledges, especially online sources, has been identified as a clear component of the decision-making processes of some PrEP users. All of these dimensions in which PrEP is embedded enable me to conclude that we are facing the emergence of a new subject in the history of HIV prevention in England, the non-positive antiretroviral gay body,

a figure that can only grow in importance within the analysis of the relationship between gay men and medicine.

Chapter 4: Configuring the PrEP response: between public health and commodity activism

This chapter argues that PrEP activism has emerged from the confluence of three different ideological lines of public health promotion in England, along with new forms of commodity activism, resulting in a historical decrease in HIV infections in England, but also a higher degree of commodification of HIV prevention. The chapter provides a description of the three models of public health – the single-issue, environmentalist and pharmaceutical models – that are key to understanding the process of implementation of PrEP in England and which emerged as a response to specific historical challenges in the management of the health of the population. The implementation of these models of public health involved the participation of several statutory and non-statutory agents and gave rise to different conceptual subjectivities related to medical citizenship, such as the "risk avoiding individual" (Rose G. 1992), the "environmentalist citizen" (Petersen and Lupton) and those subjectivities related to the use of, and access to, pharmaceuticals (Martinez-Lacabe 2019).

These three a priori, unrelated public health models converge in PrEP activism. But, what kind of challenges triggered the public health responses to HIV in relation to the necessity of implementing PrEP in England? Most important was the fact that by the late 2000s, HIV prevention policies had not been successful. Epidemiological data shows that the number of new infections in England had risen over consecutive years, impacting an even higher proportion of the gay population. In accordance with this quantitative data, qualitative data revealed an increase in gay men reporting having unprotected sex from 24.3% in 1998 to 36.6% in 2008 (Latimore et al. 2011).

In addressing this problem, perhaps the most remarkable feature of PrEP activism is that it brings to the forefront internet marketing strategies and the creation of a grey PrEP market in an otherwise extremely regulated pharmaceutical economy. While this convergence

might suggest the influence of a neoliberal ideology, I argue that this type of activism has also engendered a form of collective agency based on a pharmaceutical/antiretroviral care-of- the-other ethos, which needs to be better understood in the light of future biomedical interventions. This *care of the other*, mediated by pharmaceuticals, is an important factor to consider in the promotion of successful public health campaigns, since it promises to benefit the community through individual acts. In addition, the emergence of a spontaneous and unorganised model of peer education, linked to the idea of collective agency, needs to be analysed, as a factor that has contributed to the success of HIV reduction in England. In this sense, I will analyse the circumstances that allowed this peer education model to arise.

Historical Context: PrEP activism as inheritor of three public health models

Activist Single-issue Public Health (1950 to present)

From the 1950s until the appearance of HIV in the 1980s, there was a gradual shift in the focus of public health from infectious diseases towards non-communicable diseases in England. This shift happened as a result of the implementation of widespread childhood immunization, which dramatically reduced the number of deaths caused by poliomyelitis, diphtheria, measles, tuberculosis and other infectious illnesses. The challenges faced by the public health authorities were "new man-made" illnesses derived from lifestyles, and the threats posed by single issues such as smoking, diet or alcohol consumption. The reason for this change lay in the knowledge that certain lifestyles related to diet or tendencies towards smoking or drinking were linked to diseases such as lung cancer and coronary heart disease. Therefore, England saw the emergence of a new style of public health and the development of "state-funded activism" (Berridge 2007:16), which peaked in the 1970s. This type of single-issue public health agenda set a precedent for future biomedical governmentalities based on the idea that individuals are responsible for their choices once they have been supplied with adequate medical information.

The logic behind this type of public health is that the supply of adequate information to responsible citizens works as a preventative model, a metaphorical vaccine that counteracts human-made illnesses. This model was translated into a proliferation of government policy documents that stressed individuals' personal responsibility for their own health (Berridge 2007:207).

In order to provide information in an effective way, public health agencies intensified the use of marketing companies during the 1970s. As Virginia Berridge, claims, 'Single-issue organisations developed science-based campaigns: the role of the mass media in public health initiatives became central, as a tool to be used, or as a model to be attacked when used by others' (Berridge 2007:15). The involvement of marketing and mass media set the precedent for the future commodification of health and, clearly, played an important role in the commodification of biomedical HIV prevention methods. In England, as in the rest of Europe, although direct to consumer advertising of drugs is illegal, there has been cases in which mass media have contributed to the marketing of antiretroviral drugs. Specifically, Trivizir, a combination of antiretroviral drugs for HIV treatment, received support from the mass media. As has been argued, the mass media had a stronger impact in legitimizing the therapeutic properties of this drug than the private marketing of this drug directed to health professionals (Rosengarten 2004).

Another important trait of this kind of public health practice was the emergence of single-issue pressure groups that worked closely with the public health authorities but maintained an image 'of independence from any interests and a robust campaign stance' (Berridge 2007:166). As will be seen later in this chapter, this was clearly the case with groups that cooperated with the government during the AIDS epidemic in England, but it is also the case for activist groups that participate in the process of the implementation of PrEP in England.

Environmentalist Public Health Model (1980 to present)

Environmentalist public health activism is informed by the return of the nineteenth-century idea that the primary risks to health come from the environment, and that it is necessary to take the adequate measures to protect oneself from those dangers. Although environmentalism is mostly associated with the natural and material environment, the social environment 'regards humans as placed at risk not simply from their material surrounding but also from other humans' (Petersen and Lupton 1996:108). The PrEP response is an inheritor of this new *environmentalist* public health model that emerged in the 1980s and gave rise to the "environmentalist citizen", described as a 'rational consumer, one who engages as an autonomous individual in activities to prevent or reduce environmental damage and to protect herself or himself from health risks believed to be generated by the environment' (Ibid., p. 90).

The history of the HIV / AIDS epidemic fitted perfectly with this public health ideology, since the epidemic symbolised a revival of the fear of communicable disease (Berridge 2007), a fear that continues to this day regardless of the fact that HIV is now a treatable virus. This type of public health is not only concerned with the health of populations, but also with the health of individuals and how they can be provided with tools to protect themselves from environmental risks. The implication here is that up until the late nineteenth century, the emphasis in disease control was on infrastructures that could help to maintain a population free of illnesses, such as the construction of sewerage systems. At the end of the nineteenth century that began to change and efforts were made to educate people on how to be safe by participating in the creation of safer environments. In the case of gay men, this risky environment could be described as sexual avenues such as saunas, sex parties, dark rooms, cruising areas, etc., but should also be understood as a number of different psycho-social factors that affect individuals' decision-making processes, such as age difference between sexual partners, need for acceptance, low self-esteem, etc. Illustrating the fact that some environments

are a challenge for gay men and suggesting what triggered the PrEP response, an interviewee for this project commented on the idea that gay men were not using condoms when I asked him when he first heard about PrEP:

> So, if I fast-forward again to probably to 2015, I was in a sex club in London which isn't there now, but it was called The Hoist, and they had a very busy Sunday afternoon, called SBM which is always a busy night and I used to go there a lot, and I met a doctor who was British but he lived in America and he was using PrEP. I was often having conversations with people moaning about how so many people were having sex without condoms and I couldn't understand why suddenly everybody was barebacking, I didn't understand why it was prevalent, I didn't understand it, I was still in that mindset of using condoms.
> Question: So you saw a clear change in the scene?
> Answer: Yes, I witnessed it. Cause I've been on the sex scene very consistently since 1987, so the only break I had was one year when I was traveling from 2005 to 2006. So, I really noticed when barebacking suddenly became prevalent. So, I mentioned to this guy: People keep wanting to fuck me without condoms, why would they even think that is a good idea? And he talked to me about PrEP, he told me he was doing PrEP. and had been for a few years, and lots of people he knew in America. (Warren. Age 54. Southeast London)

This testimony illustrates how there was a shift in gay men's sexual behaviour in relation to HIV prevention practices. It reveals the existence of a public health problem and how it was being addressed by some people across the Atlantic. But it also suggests how some gay men were struggling in certain sexual environments with other gay men having unprotected anal sex. Therefore, the challenge was not only for public health agents, but also for gay men, who were put in a situation of negotiation between having unprotected anal sex or not having it. PrEP, as a form of antiretroviral medication, was embraced by many as a solution to this public health problem. Most of the interviewees for this project also revealed that they preferred having sex without condoms and that PrEP enabled them to do so, which on the other hand

might bring other public health challenges, such as the rise of other sexually transmitted infections. In this sense, the rise of syphilis diagnoses in 2019 has focused the attention of public health activists and clinicians, alerting them to potential side effects of the popularity of PrEP. In fact, the HIV prevention organization *PrEPster* has included the prevention and treatment of syphilis in their campaign "*no time no syphilis*". As will be further explained in the next section, PrEP has become *the* pharmaceutical measure to protect oneself from the environment and from other humans.

Pharmaceutical Public Health Model (1990s to present)

PrEP activism also aligns with pharmaceutical public health, which emerged in the 1990s and which saw in drugs and vaccination a solution to public health issues, along with a new frame in the relationships of the state with the pharmaceutical industry (Berridge 2007). This type of pharmacological public health has given rise to new forms of understanding citizenship (Ecks 2005) in relation not only to access to pharmacological treatment, but also to the will of citizens to engage in pharmaceutical treatment. The emergence in the mid-1990s of highly active antiretroviral therapy (HAART), which dramatically extended the life expectancy of people living with HIV, marked the beginning of new forms of understanding the epidemic, with a set of new challenges that would include the ability of gay men to adhere to the drugs. The toxicity of the drugs is raised in the following testimony by someone who started treatment in 1997:

> People were in different drug regimes, I mean I had side effects, they were quite scary but not as scary as other people were having. From the minute I started taking those drugs I didn't do a solid poo, and I was farting all the time , so it was tricky what was going to come to your ass, it was a fart or poo, or what, and the level of toxicity was so high that if I had nausea I had to find the toilet straight away because the convulsions were so strong that, if I wasn't careful I would throw up and poo at the same time or pee myself, so it was scary, but I more or less learned to live with it. (Koldo. Age 52. North London)

Regardless of the difficulty of remaining in treatment, the pharmaceutical model became the path to follow and saved the lives of thousands of people in England.

PrEP activism is based on making antiretroviral drugs for prevention available to anyone who wants them. In this sense, PrEP activism has often worked in conjunction with other social agents belonging to the field of HIV/AIDS prevention. At least, it can be said that they share the same objectives. Thus, the Terrence Higgins Trust has been campaigning for PrEP access since the publication of the results of the PROUD clinical trial. With a greater legislative push, the National AIDS Trust forced the NHS to commission a trial into the use of PrEP in England, and several HIV organizations called on the public to sign a community statement for PrEP (GMFA et al. 2014). This assemblage of actors means that PrEP activism is backed by statutory agents that are well established in the English social fabric. In this sense, PrEP activism is not in full opposition to the aims of the government, since the government recognises the value of PrEP as a means for HIV prevention. The tension between PrEP activism and the NHS lies in the fact that PrEP activists understand that PrEP, as a biomedical intervention, will be successful as long as is available to all those who want it, whereas the NHS has established a more regulated system of access to PrEP by following a risk assessment evaluation and mandatory follow ups. To conclude, PrEP activism, along with other agents, have seen in the pharmaceutical model a solution to the challenges that HIV prevention in England were facing.

Assembling the PrEP response: key sites

In general, the term activism should be understood as an umbrella concept encompassing different practices seeking political or social change. While the general perception of an activist is most likely a politically and socially progressive person, conservative social sectors also include activism as part of their strategies for change and policy making (Atkinson and Berg 2012). Moreover, the borders between the activist, the advocate and the militant are often

blurred, adding more difficulty in defining what an activist is (Bobel 2007). Taking into account the above, PrEP activism needs to be linked to health-promoting practices and public health. Perhaps one of the most important factors when analyzing PrEP activism is the fact that it arose within a traditional HIV biomedical intervention. Originally, PrEP activism could be described as a vertical process, since the promotion of PrEP in England was a consequence of the positive results of trials designed by clinicians. Later, PrEP activism took on the form of assemblage, in which different statutory and non-statutory agents interacted with each other producing information related to PrEP while creating a new form of subjectivity related to public health activism.

Thus, drawing on assemblage theory (DeLanda 2016), the PrEP activist response could be described as an assemblage of independent actors that sometimes interact together, producing new HIV prevention knowledge and subjectivities, while promoting PrEP and constructing a sourcing platform for everyone who wants and can afford it. This strategy was taken as a necessary evil while waiting for a free generalised access via the NHS.

This PrEP assemblage was formed of a diverse array of seemingly unconnected actors: small groups of HIV activists, biomedical researchers and clinicians, HIV journalists and individual PrEP advocates. The actions of this assemblage fall into the category of public health activism whose strategies have included the creation and promotion of a sourcing platform for PrEP and legal measures for implementing PrEP in England. These actors have worked, and are working, as health pressure groups with a strong political stance, critiquing the state of affairs of Public Health England and the NHS not only in terms of HIV prevention polices but also in regard to the distribution of power between central and local authorities.

Among the promoters of PrEP, two small groups of activists were instrumental in the progression of PrEP in England. The first is IwantPrEPnow.co.uk, an organization created by Greg Owen and Alex Craddok with the aim of creating a sourcing platform where people could

buy PrEP online without prescription. This group's main activity was to signpost where it was possible to buy PrEP online. The other group is PrEPster. This group was formed by several activists with backgrounds in public health and HIV activism and it supplied more medical information about PrEP than IwantPrEPnow. Both groups were initially unfunded, but in November 2007 IwantPrEPnow.co.uk was assimilated by the Terrence Higgins Trust, which hired Greg Owen, who still runs the website. PrEPster now gets financial support from the MAC AIDS FUND and the Elton John Foundation. This means that PrEP activism nowadays is mostly professional activism with no civil disobedience strategies, which favours its sustainability, since activists are not dealing with potential legal sanctions.

The clinical activist response

From the very beginning, the attempts to implement PrEP in England were shaped by the collaboration between several key clinical scientists and HIV community activists. Thus, in order to recruit participants for the first PrEP clinical trial, clinicians sought the help of HIV community activists, as stated by one of the participants for this project:

> So, the director of the trial said: do you want to help me talk to the gay community about this? You are the person who can explain this idea to movers and shakers in the gay community. So, I said, sure, ok. We did a couple of meetings together, got a couple of phone calls together and so I just re-emailed everybody I knew who was involved in prevention, including people who I already knew were hostile to PrEP because it was very important to have them in the room and we had a couple of meetings; I remember a long meeting at Dean Street Clinic where we discussed the whole idea of the study and thrashed through the protocol and people was very passionate, some people were very against it, some people were very for it, I chaired, it was exhausting (Jad George. Age 58. North London)

Drawing only on this testimony it is safe to state that it was not the gay population per se demanding a chemical treatment to prevent HIV infection, but clinical scientists along with

some members of the PrEP assemblage who initiated this biomedical intervention.

As mentioned in the introduction to the thesis, the recruitment of the participants took place in 13 different sexual health clinics, including London (eight sites), Brighton, Birmingham, York, Manchester and Sheffield. The purpose of the study was to assess the effectiveness of PrEP in a real-life scenario. In contrast to PrEP trials conducted elsewhere in the world, which had been blinded, the PROUD study was an open-label trial, meaning that both the researchers and the participants knew which treatment was being administered and, most importantly, that there were no participants who were receiving placebo doses. While prior trials had confirmed the effectiveness of PrEP in reducing HIV transmission, the PROUD study aimed to assess whether the participants would engage in riskier sexual activities as a result of feeling more protected by the antiretroviral drugs.

By 2016, some clinicians were offering support to those who were taking PrEP outside of the usual channels of the health system. This clinical support included kidney monitoring and drug monitoring tests, so that users knew that they were taking the right drugs (Paparini et al. 2018). Various interviewees for this project acknowledged the role of clinicians in giving them support, as well as the necessary reassurance to be on PrEP. Of great importance and relevance for the implementation of PrEP in England was the Dean Street clinic in London's Soho district. This clinic pioneered PrEP sourcing before the IMPACT trial was set up, provided PrEP related care and created links between users, activists and clinicians as the following interview excerpts show:

> Question: Ok, and during this time that you were buying. Did you use to go Dean Street?
> Answer: Ah, right, yes. I was very lucky with the timing of that too, actually, because that coincided with Dean Street offering support to PrEP. They started doing that pretty much at the same time, so what they were doing, because prior to that you could buy it in Dean Street at 400 pounds which I could never consider

that, but anyway, they were offering the three-monthly test so that was brilliant. That was really good that they were doing that. (Warren. Age 54. Southeast London)

Some really amazing support from the clinic. At that point, there was a new doctor that had been working in Dean Street in London who joined the Leeds service and that's, who thankfully I saw on that day. She was really supportive when I bared myself again to the second person for that on that day. Ironically, it was my birthday. So on my birthday, they told me I probably had HIV which was quite strange. She helped me then move forward so I managed to find somewhere to buy my PrEP from. It looked like it was going to be delayed coming into the country. They supported me with an extra month's worth of Truvada because that was one of the drugs they'd given me for PEP to tide me over to make sure I had enough, which was something that she didn't have to do. At that point they didn't really know how to support PrEP, she knew that they should check for proteins to make sure that the drug wasn't doing you any harm. I think I was one of the first people in Leeds that they actually said, "We'll support you with this. What we'll do is, we'll do some urine dips to check your proteins. If that's fine, then we're not doing anything else." I said, "Fine, I'll be cool with that." "If it's not we'll take extra blood and we'll make sure we get the right tests." From that point on, I've been on a revolving three-month check-up and they allow me to book my next appointment when I'm there, they just made it really easy for me to access all the right services that I need to make sure that everything is fine (Sean. Age 38. Leeds)

From the above it can be concluded that the cooperation of clinicians with PrEP users was key to understanding the process of implementation of PrEP in England. In this sense, these clinicians worked beyond their obligations in providing analytics to PrEP users. This could be interpreted an act of civil disobedience, since clinicians were using medical resources that were not allocated for it. This type of cooperation is part of a tradition of gay men influencing policy making, as is explored in the following section.

The AIDS and HIV organisations' response

The PROUD data, which was welcomed by HIV organisations around the world, became a scientifically legitimising tool for future demands for PrEP implementation in England. This demand led to a struggle between the NHS and HIV / AIDS organizations in England, who initially demanded that PrEP be made accessible to all those who needed it. Initially, the term "need" was defined by at least part of the medical criteria that would allow people to take part in the PROUD trial, that is: (1) Being HIV negative (2) Being 18 or older (3) Having had anal sex without a condom in the last three months. (4) Being likely to do this again in the next three months. (5) Being able to visit the clinic for blood tests every three months. Later on, activists would demand PrEP for all those who *want* it, since these criteria| proved challenging for some gay men. Campaigners from HIV organisations included the Terrence Higgins Trust and the National AIDS Trust, an organization that initially took a leading role in campaigning for PrEP, and which released an online statement calling for immediate access to PrEP for all those who needed it. This statement reflected the different stance of the NHS in opposition to that of the HIV organizations, PrEP activists and other campaigners:

> The NHS is still considering whether and how to make PrEP available. Community organisations working on HIV prevention have renewed calls to make PrEP available as soon as possible for those who need it most. They are calling on the public to sign the online statement at this crucial time, to tell decision makers that access to PrEP is a public health imperative and we need it now. (GMFA et al. 2014)

The statement received 4019 signatories. Another petition delivered by the Terrence Higgins Trust on the government's website, entitled "Make Pre-Exposure Prophylaxis (Prep) immediately available on the NHS", was signed by 13,104 people. The government's response indicated the necessity of evaluating the cost-effectiveness of the biomedical intervention:

> The Government is investing £2.4m in HIV prevention nationally […] With regard to PrEP, NHS England has agreed to carefully consider their position on commissioning. Planning continues on the early implementer test sites in the meantime. Whatever the commissioning arrangements for PrEP, decisions to fund will depend on full assessment of clinical and cost effectiveness and how it can be integrated with other HIV prevention efforts. *(Department of Health 2016)*[6]

But prior to this response, in March 2016, NHS England had released an "Update on commissioning and provision of Pre-Exposure Prophylaxis (PREP) for HIV prevention". The statement denied the NHS's responsibility for commissioning HIV prevention services on the grounds of the Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations of 2013, which allocate the commissioning of HIV prevention services to local authorities. Thus, the NHS was responsible for the treatment of HIV, but prevention services were the responsibility of local authorities. This statement was challenged by the National AIDS Trust, which brought the case to the High Court of Justice one month later.

The question of who was responsible for the commissioning of PrEP was at last resolved by Lord Justice Longmore, who stated that 'If NHS England has the function of commissioning treatment for HIV, the discharge of that function will be greatly helped by reducing the numbers of persons infected with HIV' (Longmore et al. 2016). Lord Justice Underhill concluded that although the NHS is not 'obliged to commission PrEP' it had the power to do so (Ibid., para.59). As a consequence of the pronouncement, NHS England's Director of Specialised Commissioning and Deputy National Medical Director, Dr Jonathan Fielden, announced a new clinical trial that he defined as 'a new ground breaking national

[6] https://petition.parliament.uk/archived/petitions/113891

programme for PrEP that will benefit at least 10,000 people'.[7] On this occasion, NHS England took the responsibility for the funding while announcing that they would work in collaboration with 'local authorities, the Local Government Association and Public Health England to implement the findings as part of a wider national rollout'.[8] This decision was welcomed by Deborah Gold, Chief Executive of the NAT, who in a press release stated: 'We are absolutely delighted that following our wins in Court, NHS England, working with Public Health England and local government will be now making PrEP available on a large scale, and quickly, to those who need it'.[9]

From all the above, it can be inferred that the last reorganization of the NHS, which granted the commissioning of sexual health preventive services to local authorities, made the rapid implementation of PrEP in England more difficult. It can also be concluded that this agreement to make available PrEP through clinical trial was mediated by HIV pressure groups. It is estimated that, up to the roll out of PrEP by the NHS in March 2020, half of the population who was on PrEP bought it online and the other half were taking PrEP through the IMPACT clinical trial. This means that until the final implementation of PrEP, the phenomenon of PrEP in England was located somewhere between the commodification of HIV prevention and a clinic trial model that aimed to be as inclusive as possible.

Boosting DIY PrEP practices: "We need to create a demand"

The demand for PrEP in England was created through a number of actions that incorporated professionals from several branches of HIV knowledge production. Thus, during the summer

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[7] https://www.england.nhs.uk/2016/12/hiv-prevention-pregramme/

[8] Ibid.

[9] http://www.nat.org.uk/press-release/nat-welcome-new-hiv-prevention-drug-funding-after-court-win

of 2015 there were several screenings of a documentary about the first PrEP clinical trial in England. The premier of this documentary — funded by the Medical Research Council, a UK government agency, and directed by Nicholas Feustel — took place at the Cinema Museum of London in July 2015. Feustel opened the event explaining to the audience that one of the aims of the study was 'to know if gay people would be able to take a pill every day' answering that 'apparently we can' (Feustel 2015). Clearly, this was an ironic statement that addressed the issue of adherence to the treatment, which had been proved challenging in prior clinical trials. His comment also reflected harmful stereotypes among public health authorities which imagine gay men as irrational / irresponsible actors struggling with self-care.

Following the public health model that blossomed in the 1970s, the documentary provided scientific information about PrEP, but it also exposed how PrEP affected the lives of those who were taking it. Moreover, the documentary gave a clear idea of who some of the actors involved in promoting PrEP in England at that moment were. After the screening, there was an open discussion with a panel composed of Gus Cairns (community activist and NAM Editor), Charlie Witzel (PROUD participant and Research Assistant at Sigma Research) and Gregg Mitchel (PROUD trial participant). During the event, there was a call for a demonstration the next day demanding NHS access to PrEP for those who need it. ACT UP London participated in the event and mainstream media began to cover the debate on PrEP for the first time.[10]

Berridge, referring to the predominant public health model in the 1970s, stated that "the role of the mass media in public health initiatives became central, as a tool to be used, or as a model to be attacked when used by others" (Berridge 2007:15). This was the case for PrEP in England. The media did a good job covering what PrEP was (Paparini et al. 2018), and it also

[10] http://www.bbc.co.uk/news/magazine-33346746

created the space for a public debate. Online and media debates about the legitimacy of using public money to fund PrEP, which is a prevention tool, versus using funding to cover NHS treatments, were frequently characterised by moralizing opinions, especially by those opposed to the NHS funding PrEP. Thus, on August 2016, the *Sun* published 'What price health? NHS warns other care is at risk because of HIV drug and vows to appeal High Court decision' and followed with a sub headline: 'Cancer patients and children with cystic fibrosis are among those who could lose out after NHS England was told it should fund Prep'.[11] This type of moralistic attack had also been a frequent occurrence during the first years of the epidemic in England, including on public television. In his review on the role of media during the AIDS epidemic, Simon Watney (1987) provides multiple examples in which the media contributed to the fabrication of a hierarchy of blame and responsibility, differentiating between innocent and non-innocent victims. Moreover, Watney is also critical of most of the media with regards to the creation of fear and the reasonability of the data they broadcast and explained that 'such stories are invariably accompanied by denials that Aids can be contracted via casual contact, but their framing is always top heavy, focusing on fear rather than allaying it, dramatising anxiety rather than alleviating it' (Watney 1987:39).

Public television took a completely different position on PrEP decades later, but sometimes reproduced images from the past of the epidemic when being HIV positive had a completely different meaning than during the PrEP era. One participant explained how the media's coverage of PrEP was mainly addressed to a sector of the population:

> Am I happy with the media? Sort of, it depends. Like I'd say, generally, the gay press has been great. The straight press? Not so much. I mean, the BBC have been covering every angle on it. Well, every development, like it's on our website now

[11] https://www.thesun.co.uk/news/1547570/nhs-warns-other-care-is-at-risk-because-of-hiv-drug-and-vows-to-appeal-high-court-decision/

> so it's been accurate. In that respect, it's fine. I just think you've got to work hard to make people care to the general audience. That's what I'd say. (Ron. Age 36. London)

This testimony suggests that the BBC coverage echoed the logics of epidemiological public health by making the gay population the focus of PrEP news. This testimony also acknowledges that public television has covered extensively 'every development' of PrEP and, therefore, there was information for those who could access it. It also suggests that in order to make the general population care about PrEP, the media had to make a bigger effort. The following testimony from a participant in this study reveals a different opinion regarding the effect of the media at a moment when PrEP was still not funded by the NHS. I asked the participant how he felt about the government in relation with the process of PrEP implementation in England:

> Angry that they tried not to fund it, but I am more angry at the press like the *Daily Mail*, who called it a lifestyle drug, so that gay people can have unprotected sex whenever they want. People like CJ, who is a police officer for thirteen years, he says: oh! PrEP is just a way to have unprotected sex with everyone. But you are part of the problem. You are the problem, because you believe that PrEP is there purely to allow us having unprotected sex and is not, what about African women? you know, because growth in HIV is not just about gay men […] Sex workers, you know, people who are allergic to latex, there's lots of groups out there and it's not about just having unprotected sex with whoever you want, it's about stopping the biggest disease, the biggest virus is attacking our communities right now, is not about unprotected sex. The NHS don't want to fund it, and then the press got a hold of it and they were like : 'oh it's a lifestyle drug so that gays can have sex parties', and then people in the gay community started even believing that shit, and it's like how can you believe that it's true and it's like: 'we do have sex with lots of people' and I'm like: 'that's your opinion because that's your life'. (Carlo. Age 39. East Croydon)

From the previous testimonies it is clear that there were different treatments in the media about PrEP and that gay men had different perceptions. This is well evidenced in a qualitative study of UK newsprint articles between 2012 and 2016 that confirmed how scientific data was used to produce two different narratives regarding PrEP: ‘ ir/responsible citizens focused on imagined PrEP users and their capacity to use PrEP effectively; and the public health imperative, which described the need for PrEP’ (Young et all. 2020:1). From this article, and the testimonies in this study, it can be deduced that the press also had a role in opening lively debates about PrEP among part of the gay population.

After the trial and its documentary in 2015, the demand for PrEP was beginning to rise thanks to, or perhaps despite of, the role of the media, and it became clear that public health activists had to act in order to make PrEP accessible to those who wanted to access it. As mentioned at the beginning, two small activist groups played a large role in creating a sourcing platform for those who wanted access to PrEP*:* IwantPrEPnow.co.uk and PrEPsters. The role of social media in marketing PrEP became a crucial strategy in public health. As has been largely acknowledged by scholars of biomedicalisation, the internet has had a profound impact on the ways in which medical knowledge is disseminated. Greg Owen, co-founder of Iwantprepnow.co.uk, who has an academic background in marketing, clearly states the importance of deploying different strategies to market PrEP:

> I know how social media works. Even when I look like a crazy person, I was aware people are going to think I was crazy, but at least they're like, "Let's check in on what he's doing today." It was all about PrEP stuff. It was the cheapest, and the only way I could create any interest around PrEP was to make it seem like I was this bonkers dude who was just doing crazy shit. I did do a lot of crazy shit, but all of it, it's real, but it just-- I think people now, this year, certain people in this sector have been able- because I had to change, because now I'm founding an organisation- people are like, "You've changed." I'm like, "No, I changed my delivery." (Greg Owen, Personal Interview. Age 36. London)

Owen refers to the strategy that any publicity is good publicity. He might also refer to his decision to stop taking his medication for HIV treatment as a form of protest in support of other gay men who could not access to antiretroviral drugs for HIV prevention. His work as a PrEP activist has been largely acknowledged by the media, including the BBC,[12] and he has been referred to as a hero and the person who helped to save the lives of thousands of people (Piazza 2016).[13] The narrative of the hero is clearly one that helps to legitimise PrEP activism, but as Owen stated himself in an interview for Sky news, it is HIV treatment and not prevention that saves lives.[14] In summary, the role of the media has been fundamental in the process of creating a demand for PrEP. Moreover, a social debate around the responsibility of the NHS to fund PrEP arose as a collateral effect of using media to make PrEP known as well as marketable.

Another important fact in the PrEP response is that HIV community-based activists are often perceived as altruistic volunteers distant from institutional power and lacking personal or economic interests in the campaigns. This perception of community-based activists as powerless individuals works as a legitimizing element that helps people to engage in self-governance practices with the feeling that what they are doing is not only right but also good in terms of social justice. The following testimony reinforces this idea of the selfless activist. The theme came up when I asked a participant if he remembered the moment in which the bottles of PrEP arrived home:

> Yeah , well, kind of. I don't know what I felt. I felt I got this far being HIV negative, so I've got to get this bit right. And I remember being very impacted by Greg's story. I was aware that he was going to make a video diary of being on PrEP and then of course, he went and he got that test and he was positive and you know, I was just, I really felt for him, I thought he just got ready to take PrEP and then this

[12] https://www.bbc.co.uk/news/stories-44606711

[13] http://boredomtherapy.com/man-website-move

[14] https://www.youtube.com/watch?v=EvoPcKdeHDc

> is happening. And I do really kind of, in my head in a way, for having the drive and the conviction to put all that energy into PrEP campaigning, when in some ways it would be so easy to not do so, because it's a selfless part, really , because he is not directly benefiting from PrEP himself. (Warren. Age 54. Southeast London).

In this sense, the media also contributed to creating this image when referring to Greg Owen, who was introduced in the media as the unemployed and homeless gay man.

Along with the previously explained types of public health traditions in England, PrEP activism embodies a new form of commodity activism that has resulted in a higher degree of commodification of HIV prevention while contributing to a historic fall in HIV diagnoses. This section delves into the paradoxical process of the commodification of PrEP in England, in which PrEP activists and advocates used and adopted market techniques and language to provide PrEP access to the largest possible number of users. Thus, once the results of the PROUD trial were published, HIV community activists organised several participatory events; however, these reached a limited number of gay men in England. The events consisted of the projection of documentaries about the PROUD Trial, with the presence of a roundtable composed of HIV community activists and PrEP users.

In the biomedicalisation of HIV prevention in England, the voices of services users and consumers have become a mandatory element in a variety of ways with a range of different consequences. For example, there is often a transformation at the level of subjectivities from passive objects of study to active subjects of biomedical interventions. The voice of PrEP users in those participatory events contributed to the normalisation of the consumerisation and marketisation of PrEP. In relation to this, PrEP activism needs to be understood as a form of commodity activism that brings to the forefront marketing strategies linked to the internet. Regardless of what could be seen as a neoliberal phenomenon, this type of activism has also engendered a form of collective agency based on a pharmaceutical / antiretroviral care of the

other ethos through a spontaneous peer education phenomenon. In England, the practice of buying PrEP online without prescription or medical consultation has been defined as DIY PrEP. This practice seems to fit nicely with the concept of commodity activism, an activism where 'brand culture, commodity culture, activism and humanitarianism are blurred' (Sturken 2012:ix). The question that arises here is: how is the creation of a grey market a practice of social transformation? In the book Commodity Activism: Cultural Resistance in Neoliberal Times, Marita Sturken points to the necessity of addressing the paradox of activism in the neoliberal era:

> Contradictions are inevitable here. Activism as consumerism. Celebrity humanitarianism. Commodity-driven social resistance. Neoliberal activism. Yet, (…) seeing it all as contradiction does not help us anymore, (…) a sense of contradiction is derived from remaining in an outdated mode of thinking. We cannot dismiss these modes as simply hypocrisy, incorporation, or corporate appropriation. They demand a more complex, less cynical, less dismissive approach. Indeed, these very practices of consumer activism demand a recognition of the key relationship of consumerism and affect, the emotional content of consumer transaction (Sturken 2012:ix).

As this quotation suggests, analysing PrEP activism in England as a mere neoliberal adaptation of previous forms of activism risks producing sterile stereotypes. It is instead essential to understand the tensions between the economic forces that create inequalities in access to health prevention methods and the reality of the success of a biomedical intervention that contributed to a historical fall in HIV infections in England. Regardless of such a historical fall, it is also necessary to acknowledge that the intervention was not perfect. To understand such tensions, I will focus on the factors that have contributed to making PrEP a marketable HIV prevention device. One of the keys to the success of the process of implementation of PrEP in England has been the efforts made to make people understand PrEP as a medical commodity that can

be purchased like any other commodity on the internet. In a public health system where health services are conceived as free, at least at the point of access, such versatility could be criticised as an intrusion of market rules. However, according to biomedicalisation theories, there has been a reconfiguration of the liminal space and the legitimate frontiers between public medicine and corporate medicine (Clark et al. 2003). This reconfiguration is in part what has made PrEP more successful than previous prevention interventions. In fact, some gay men perceived the commodification of PrEP as something good, as existing qualitative studies have pointed out (Young et al. 2016; Martinez-Lacabe 2019).

There are four factors that have contributed to the process by which PrEP has been characterised as a medical commodity. Firstly, the role of e-pharmacies has been fundamental to the creation of a PrEP grey market in England. The refusal of American biotechnological company Gilead Sciences to bring down patent prices in England shaped negotiations with the NHS, which, at the same time, began a legislative struggle to define who was responsible for commissioning PrEP. A PrEP activist interviewed for this project discussed the role of pharmaceutical companies, specifically Gilead, in the process of implementation of PrEP in England:

> It's interesting that you talked about PrEP facts because that's primarily a US focused Facebook group and I think what's going on in the States is really interesting around PrEP, because I think there is a pharmaceutical push, and that'd been Gilead funding trial sites or implementations sites, I think they're called, and lots of people are getting PrEP free or subsided through these sites, and obviously Gilead might be interested in cornering a PrEP market. I think the role of pharmaceuticals in the US is very different from how it's been here […]. I think we would see something quite different if pharma had bought into PrEP here, rather than resisting PrEP here, and I think if we hadn't all of the stuff that is going on around patents expirations with Gilead then I think things would be quite different here. I think we would have seen a lot more pharmaceutical companies, Gilead, in particular, promoted, as much as the [inaudible] here, I think organisations like

> PrEPster or IwantPrEPnow, more grassroot organisations would have Gilead putting money into us and promote PrEP (Logan. Age 48. London).

The previous testimony is a reflection on the different approach that Gilead took in England, where, unlike the United States, there was no push for the implementation of PrEP, but on the contrary, there was a resistance in the form of patents. As a result of this situation, the search to find pharmacies that could supply PrEP online began. The website recommended initially by PrEP activists and some clinicians to buy generic Truvada in England was *Dynamix International*. This company, as stated on its website, 'is owned and operated by a PrEP activist who works closely with and supports other PrEP activists and PrEP groups around the world' (Dynamix International 2020). Their aim is 'to make PrEP accessible and affordable to as many people as possible in as many countries around the world as possible' (Ibid.). The website, however, sells not only PrEP, but also other drugs such as generic Viagra and Doxycycline, in what represents an example of a grey market of generic drugs, commodities and activist entrepreneurship. However, some of the participants in this study expressed their anxiety that this website would not have enough resources to provide a continued supply of PrEP—an issue that actually occurred after some years and that could have potentially created a public health problem.

Currently, the website *IwantPrEPnow.co.uk* includes several options for those who want to buy PrEP. Most of these sellers do not require a prescription to be uploaded to buy PrEP. However other sellers do require some paperwork before the sale can be completed. Moreover, as the page states, the Mags Portman PrEP Access Fund offers free PrEP to those who cannot afford to pay for it. All of this is possible because the UK legal framework allows for the importation of medicines without prescription, as long as they are for personal use and do not exceed the stipulated treatment of three months. This is unique to the United Kingdom and would constitute an illegal practice in many countries. Moreover, in the realm of HIV and

AIDS treatment, importing drugs is not a new phenomenon (Lindeman 1994). It was previously done in England in the 1980s during the AIDS epidemic (Watney 2017).

The second factor that has contributed to PrEP becoming a medical commodity is that, in contrast to the prescription process for other antiretroviral drugs for the treatment of HIV, the fact that buying PrEP online does not require a prescription strongly favors its marketisation. In HIV treatment, a medical doctor decides what type of medicines are appropriate for a person living with HIV. Of the seven groups in which antiretroviral medicines are classified, a person must take a combination of at least three drugs from at least two of those groups. In short, prescribing antiretroviral drugs for HIV treatment is a customised process that depends on several factors that include possible side effects or interactions with other medicines. The universalised PrEP regime favors its marketisation since "one pill fits all" bodies.

Thirdly, it is possible to talk about a historical process of gay bio-governmentality that involves the production of new subjectivities founded on the perception of HIV prevention services as commodities and the reconfiguration of patients as users/consumers (Rose 2007). In this sense, the sexual health clinic has been compared to an 'enterprise that has a series of sexual health products and services that are available to individuals' (Pryce 159). Examples of this are HIV test kits, PrEP and other sexually transmitted infection screening services.

Fourthly and finally, the marketisation of PrEP has involved a certain level of branding, which is an irrefutable sign of the commodification of PrEP. But, more importantly, it reveals a strategy to reach a larger number of users/consumers. This strategy of market-based approaches to health access highlights the relational aspect between a product and the identification with the product of those who consume it.

The emergence of peer educators as collective agency

In England, peer education as an approach to health promotion in the realm of HIV prevention

has had mixed outcomes (Elford et al. 2001; Elford et al. 2002). As an intervention, it is also difficult to measure its efficacy. However, some authors have pointed to the necessity of creating empowering social environments as a requisite for successful peer interventions (Cornish and Campbell 2009). From the interviews in this study, it is possible to conclude that a spontaneous form of peer education emerged between PrEP users. The use of apps enabled this kind of peer education, as exposed in the following quotes by two different participants in Leeds and Brighton:

> Then, as it became normalised for me, it was then about, well, how then do I help other people? How do I make sure that other people have the right kind of resources, that they have access? It could be something as simple as someone on Grindr will say 'I am negative and on PrEP'. In fact, the guy that I've just started seeing, he didn't know a whole lot about it, and he said to me that he'd seen it on other people's profiles but never pressed the little information button next to it. On mine, because he knew me, he pushed the button and was like, 'Wow'. He's again just asked me about, 'Can I ask you some questions?' I said, 'Of course you can. Ask away'. I've been able to point him in the direction of some resources, so he can go and do his own research, and work out whether it's right for him, and whether he wants to start taking it. I moved from that whole education for myself into now helping others get educated about PrEP and work out whether it's the right thing for them to have. (Sean. Age 38. Leeds)

From the testimony above, it is possible to state that peer education among gay men online worked at different levels. People would use gay apps to validate information that they had read in other places, regarding, for example, how to get access to generic Truvada or what the side effects were. This was also a way of seeking reassurance and the locus for starting up decision making processes, as well as to take care of the community. The following testimony illustrates the case of a gay man who educated himself, with another person, about PrEP:

> I feel like I've been home, what's the word? Not exactly home-schooling, but doing it very much on my own, without really engaging with the proper healthcare situation but again, I feel like the guy that I was chatting to about starting PrEP is a medical doctor. He'd also read up on some things as well, so between us, we agreed that it's probably not a big risk in terms of kidney function. We've had a negative test recently, that's the most important thing (Liam. Age 39. East London).

This testimony describes a situation in which some gay men are not fully following the PrEP protocol that includes previous kidney and liver monitoring. Although both persons claimed to be medical professionals and it was probably a safe approach to take PrEP, this testimony makes clear the possibility that other people are using generic Truvada without carrying out the rest of the PrEP protocol, which might pose a potential risk to their health (Brisson 2018). The most interesting aspect of this type of peer education is that it arose spontaneously as a sort of collective gay agency and not as a traditional public health intervention. This collective agency was facilitated by new technological ways of initiating relationships among gay men, but obviously this agency was co-constituted by gay men's perceptions of what PrEP means, and it would not have been adequate to talk of a merely technological determinism (Smith and Marx 1994). In this sense, the fact that PrEP was perceived as a miracle drug by some of the interviewees, due to its proven efficacy, also facilitated the rise of a collective agency and the emergence of technoscientific identities related to PrEP activism. The following testimonies, which include one of the opening quotes for this thesis, encapsulate this type of technoscientific identity:

> In a way for me, PrEP is a miracle drug. Five years ago, if someone said, "If we could invent this, would people want it?" I would be like, "Who wouldn't want it?" We've not really seen it come into proper use yet, but still ultimately how to access it, the barriers in the way are there. People are ashamed and reluctant and, "What does this say about me? What more does this say about me?" kind of thing (Leo. Age 40. East London).

> Question Could you always afford to buy it?
> Answer: I mean, it's a bit of stretch, because I don't own a lot of money, but the forty-five pound a month, I was always sort of willing to try to afford that, cause I felt the payoff was so great. So … and also, I suppose in a way, I became passionate about it quite quickly so, I sort of wanted to buy 'cos I wanted to be part of the change really. (Warren. Age 54. Southeast London)

This last testimony reveals that for the interviewee, being on PrEP involved more than a safe sex approach to sexual practices or a medical commodity. It involved being "part of the change" that some gay men perceived as an intrinsic part of the HIV activist tradition. Nevertheless, commodity activism needs to be carefully framed within the specific challenge that HIV prevention in England faces. This type of approach that involves a financial personal commitment in order to access PrEP should not be the norm in response to the lack of pharmaceutical provision, since it sets a precedent in terms of the transfer of economic responsibilities in the realm of health provision.

Conclusion

This chapter has focused on locating PrEP activism within public health traditions in England. As it has explained, those three traditions—the activist single-issue, the environmentalist and the pharmaceutical— have not only provided theoretical space to develop HIV prevention strategies in England, but have also produced and offered a number of HIV prevention related subjectivities that have conditioned the success or failure of HIV prevention interventions. In relation to the production of subjectivities, Mitchell Dean explains that

> Subjectivities are positions we are more or less offered, and that we might even offer ourselves, that we might fully embrace or that we might embrace with less enthusiasm, more cynicism, irony, etc., but which we should never imagine are what we are. In this sense I start from the proposition that we are never completely what we imagine ourselves or take ourselves to be. Thus, we are never the self-

> governing subjects that various programs, practices, and technologies would want us to be' (Dean, Personal Communication).

Although I agree with Dean's view on subjectivities, I consider it of great importance to acknowledge that those positions that gay men have been offered in relation to HIV prevention strategies produce multiple debates among the gay population in England. These positions contribute to the creation of mentalities that might produce resistance when new positions are offered.

Against this background of co-existing public health models, PrEP activism emerged as a demand to make PrEP available on the NHS. In the process of pursuing this goal, PrEP activism took the form of an assemblage of statutory and non-statutory agents formed by key clinicians from the NHS, two online groups that provide information about PrEP and how to get it, HIV journalists, people pertaining to HIV organisations and charities, and finally PrEP users who spontaneously took an online peer educator role in dating apps. This activist assemblage reflects how diverse and broad the concept of a PrEP activist is.

Thus, the testimonies of the participants in this study provided enough data to understand that some PrEP users have required the use of new forms of activism linked to practices that can be identified as neoliberal. However, such testimonies suggest that such practices have emerged as a kind of collective agency in response to a particular challenge: the lack of provision of antiretrovirals for all those who require them. In this sense, PrEP activists used market techniques that characterised PrEP as a medical commodity. This was not perceived as negative by the participants in this study but was seen as a way to resolve the problem of access to PrEP. Creating a grey market for PrEP was a way of getting around the government controls in England and it should not be understood as a mere neoliberal action. It might best be understood as trying to bypass the neoliberal state without actually challenging it directly.

Moreover, the type of collective agency that emerged was perceived much of the time as a way to support the community through the sharing of information. In this sense, dating applications played a fundamental role in the emergence of a novel form of peer education that was co-constituted by technoscientific advances in the distribution of medical knowledge and personal perceptions of PrEP as a successful prevention method, which was described by some participants as a medical miracle. From the testimonies in the study it is possible to state that online peer education among gay men worked at different levels. Participants would use gay apps to validate information that they had read in other places, regarding, for example, how to get access to generic Truvada or what the side effects were. But this spontaneous peer education was also a way of seeking reassurance and the locus for starting up decision making processes, as well as a way of community building.

Chapter 5: The PrEP subject and the neoliberal question

> In neoliberal reason and in domains governed by it, we are only and everywhere homo oeconomicus. (Wendy Brown 2015)

> We're all supposed to be happy consumers these days, and this, alas, all too often includes the idea of consuming one another. If the marketplace is the dominant metaphor for thinking about social relations, it follows that people will be increasingly encouraged to think of themselves primarily as entirely free individuals in complete control of all their choices as consumers. This is hardly conducive to thinking about collectively shared responsibilities, whether in relation to HIV or the environment or any other issue you might care to name. (Simon Watney 2013)

In the last fifteen years, there has been an increased academic interest in conceptualizing the figure of the neoliberal sexual actor, a sexually active gay man who embodies neoliberal values of personal responsibility, market choice, rational risk analysis and personal entrepreneurship (Adam 2005, 2006; Adam and Rangel 2016; Thomann 2018; Sandet 2019). Most of this work has focused on gay men's sexual behaviors and attitudes within the realm of HIV prevention. But what does it mean to be a neoliberal sexual actor? How does neoliberal ideology shape PrEP practices for gay men in England? What are the implications of being a neoliberal sexual actor for the self, for others and for HIV prevention? Lastly, and most importantly, how adequate and useful is it to use the model of the neoliberal sexual actor to understand PrEP subjectivities in England?

This thesis places a great emphasis on this subject, since there is a need to disentangle the concept of the gay neoliberal sexual actor in relation to PrEP practices in England. Moreover, this chapter aims to challenge the validity of such an approach when applied to human subjects. Thus, as I have explained in the methods section, some of the questions that the participants in this study had to answer were designed to address the relationship between

PrEP practices and so-called neoliberal values. It did not come as a surprise that neoliberal rhetoric was present in many of the testimonies of the participants for this study. For example, when responding to the question about what they liked most about PrEP, some participants used the language of consumerism when they referred to the ability to choose between using condoms or not that PrEP confers. Others referred to how PrEP enabled them to be responsible not only for their health, but also for the health of the community. Other answers illustrated personal histories related to rational risk management or the value of education as a means for personal entrepreneurship. This concept of personal entrepreneurship, which will be further developed in the next section, is linked to forms of self-understanding in business terms, where one has to invest in education and work experience in order to succeed in a competitive society. This is typical neoliberal language, but how does the deployment of this neoliberal rhetoric turn someone into a neoliberal actor?

This chapter begins by examining the different meanings and uses of the term neoliberalism and provides an overview of the adoption of the concept of responsibility by proponents of neoliberal policies, as personal responsibility has been a key concept in HIV prevention strategies since the beginning of the HIV / AIDS epidemic (Dodds 2002). In addition, testimonies provided by participants who focused on responsibility will be analysed to elucidate the advantages and disadvantages of constructing PrEP users as neoliberal sexual actors. The chapter ends by looking at the ways in which the participants manage risk through PrEP and how they understand risk. In so doing, it determines whether the concept of the neoliberal sexual health actor can enhance our knowledge of the production of subjectivities in the realm of HIV prevention.

The neoliberal muddle: from liberalism to neoliberalism

Before commenting on what neoliberalism is, it will be helpful to shed some light on the definition of its antecedent, classical liberalism, and then move forward to describe the

differences and similarities between the two concepts. Classical liberalism can be defined as a political and economic current that emerged in different European countries in the later eighteenth century as a post-feudal / pre-capitalist response to engrained authoritarian aristocratic regimes. Although classical liberalism took different forms in different countries, liberalism, as a political project, broadly enacted ideas of equality, advocating for the acquisition of rights such as 'universal' suffrage, which at the time meant the right to vote for men who were landowners (Tribe 2009).. However, liberals had a complex attitude towards 'universal' rights and suffrage, as the concept of property-owning democracy suggests.

Classical liberalism also gave rise to the concept of citizenship. In this sense, liberalism put a great focus on the individual's rights as a reaction to the states' accumulation of power that was experienced as a threat to individual liberties. From this type of reasoning arises a long tradition for the fight for rights that includes the gay liberation movement in England. In this sense, most contemporary political subjectivities in England, and also much of Europe, are the inheritors of those liberal ideas. Therefore, it is not unreasonable to state that anytime that we talk about gay sexual "actors" and "agents" endowed with rights, we are talking about products of classical liberalism's ideas. However, in the next section on neoliberalism, I will argue in more depth why the current notions and interpretations of neoliberal actors and agents, despite sharing some characteristics, differ from the representation of the classical liberal actor.

Classical liberalism, as well as neoliberalism, go beyond the development of economic policies. Liberalism can be understood as a type of government through freedom. It is in this way that abundant scholarship refers to it as governmentality, and as exercise of government through the 'rule of freedom' that essentially refers to self-governance (Joyce 2003). The mechanics of governmentality have been largely explored in the methodological chapter of this thesis, but for the purpose of this chapter it is convenient to highlight that liberalism, in the governmental, rather than in the merely economic, sense adds a new dimension to other

traditional forms of power, namely absolutist power and disciplinary power. And it is because of this power-related aspect that liberalism is the object of copious moral analysis. The following quote from *Self-help*, a classic text of the Victorian period, encapsulates several classical liberal values while advocating for the idea of a free individual responsible for "his" own well-being and progress:

> Even the best institutions can give a man no active aid. Perhaps the utmost they can do is, to leave him free to develop himself and improve his individual condition. But in all times men have been prone to believe that their happiness and well-being were to be secured by means of institutions rather than by their own conduct. Hence the value of legislation as an agent in human advancement has always been greatly over-estimated. To constitute the millionth part of a legislature, by voting for one or two men once in three or five years, however conscientiously this duty may be performed, can exercise but little active influence upon any man's life and character. Moreover, it is every day becoming more clearly understood, that the function of government is negative and restrictive, rather than positive and active; being resolvable principally into protection, — protection of life, liberty, and property. Hence the chief "reforms" of the last fifty years have consisted mainly in abolitions and disenactments. (Smiles 1859)

This excerpt reveals the distrust of liberal thinkers towards government institutions and especially towards the production, in a general sense, of regulatory legislation rather than a regime which protects only basic rights. The text also emphasises the importance of conduct itself as an engine for thriving in life, while demanding that the government serve to ensure the 'protection of life, freedom and property'. Indirectly, the text is also a plea in favour of individualism. As a consequence of this belief and moving from the political/social realm into the specifically economic one, the demand for the deregulation of government arises as a basic condition for the better development of entrepreneurship. Deregulation is a shared value between those who advocate for neoliberal policies, but, as will be explained later, the

privatisation of certain services paradoxically entails further regulation. The following section locates the origins of neoliberalism and compares its economic and political rationality with that of classical liberalism.

Neoliberalism

Perhaps it is necessary to highlight, even at the risk of stating the obvious, that neoliberalism arose from a historical context that differs radically from that in which classical liberalism arose. By the 1940s, many of the political demands of the early liberals had been met while economic power had been considerably redistributed. This is important to remember, because free trade supporters do not make a bold distinction between neoliberalism and classical liberalism. Nevertheless, it is widely accepted that neoliberalism has its roots in the interwar period of the twentieth century and that, originally, it was understood as an economic doctrine, although it had a political breakthrough in the decades of the 1970s and 80s (Stedman Jones 2012). Marxist perspectives agree in stating that neoliberalism can been defined as a set of economic practices in which it is believed that human beings can be better developed through entrepreneurial skills in a context of competitively liberated and deregulated markets with minimal state intervention (Harvey 2005:2).

As mentioned before, some scholars support the idea that neoliberalism should be called classical liberalism, but for the purposes of this chapter, I consider it necessary to delve into the differences between these two concepts, since i) the historical context has been profoundly transformed and ii) this chapter engages with scholarship that views the neoliberal sexual actor through a different lens. Thus, for some authors, the difference between these two concepts must be found in their different economical, but, above all, political rationalities. While it is true that both forms embody a form of government based on the idea of free individuals, the prism of neoliberalism focuses on the commodification of everything, since the idea of the market as a self-regulatory entity is understood as always more efficient than

governments' interventions. The neoliberal intervention refers to the creation of the necessary conditions to reproduce market conditions:

> For early liberalism, to govern properly involves pegging the principle for rationalizing governmental activity to the rationality of the free conduct of governed individuals themselves […] for neo-liberalism, the rational principle for regulating and limiting governmental activity must be determined by reference to artificially arranged or contrived forms of the free, entrepreneurial and competitive conduct of economic-rational individuals. Here again the rationality of government must be pegged to a form of the rational self-conduct of the governed themselves, but a form that is not so much a given of human nature as a consciously contrived style of conduct. (Burchell 1996:23-24)

So, a factor that makes distinguishable both concepts, is that neoliberal ideologies put the responsibility on the government to create the necessary conditions for (that) entrepreneurial conduct to thrive (Barry et al. 1996:10). In this sense, neoliberalism has not the antigovernmental stance held by classic liberals such as Smiles. In neoliberal rationality, the government has to be productive enough to create new types of markets in areas traditionally regulated by the state. For example, privatisation facilitated this process in a defined historical period preceding the breakthrough of neoliberalism in the 1970s and 1980s. Thus, in recent decades, many liberal democracies have experienced the privatisation of natural resources and social services and the transfer of the management of health systems from the public to the private sector. In these countries, the role of the neoliberal state is to ensure the functioning of these markets through legislative, administrative, military and police apparatuses (Harvey 2005:17). Some authors have drawn on the notion of legislative apparatuses to construct theories of the "neo-liberal state" (Plant 2010) although neoliberal policies are always contested or accepted in various degrees by citizens.

In opposition to this view, supporters of the contemporary interpretation of classical liberalism argue that deregulation is not happening as often as it is said by critics of the neoliberal state. A strong example supporting the non-deregulation of policies would be the last Health Act passed in the UK, which is clearly a more extensive document than some of the older versions. However, this further regulation is a consequence of the government's attempt to adopt a market structure for the NHS. In this sense, regulation is favoring free- market approaches in opposition to more government-oriented approaches. For example, Section 75 of the 2012 Act explained that regulations might be imposed to 'protect and promote the right of patients to make choices with respect to treatment or other health care services provided for the purposes of the NHS' (England 2012:99).

However, as happens with classical liberalism, neoliberalism can be understood as something more than a set of liberal economic practices. It can be understood as a political rationality that makes possible the development and implementation of economic policies but also extends market rationality into all the aspects of human life (Brown 2003). This is a distinct trait that differentiates classical liberalism from neoliberalism. It embodies the classical governmentality paradigm in which the state assumes that citizens are rational subjects, and that, by supplying them with adequate information, these citizens, or "neoliberal subjects", will be able to care for themselves by making the 'correct' choices (Brown 1995; Avila 2014). This neoliberal subject is (the) *homo oeconomicus* as defined by Michel Foucault:

> In neo-liberalism—and it does not hide this; it proclaims it—there is also a theory of homo oeconomicus, but he is not at all a partner of exchange. Homo oeconomicus is an entrepreneur, an entrepreneur of himself. This is true to the extent that, in practice, the stake in all neoliberal analyses is the replacement every time of homo oeconomicus as partner of exchange with a homo oeconomicus as entrepreneur of himself, being for himself his own capital, being for himself his own producer, being for himself the source of [his] earnings (Foucault 2008:226).

As Foucault suggests, neoliberalism has produced its own type of homo-oeconomicus. Broadly speaking, homo oeconomicus is commonly interpreted as a rational subject who acts in their own interest in the face of information presented in economic terms. While the behaviour of homo oeconomicus or (the) "economic man" is recognizable throughout history, the concept originated as a reaction to the work of John Stuart Mill, who described it as a 'hypothetical subject, whose narrow and well-defined motives made it a useful abstraction in the economic analysis' (Persky 1995:223). A key question of this chapter lies in the appropriateness of using economic analysis for sexual behaviors. The neoliberal homo oeconomicus is characterised as capital himself, a risk calculator, an individualistic being who is not a partner of exchange and therefore is a stranger to the values of solidarity. In sum, this analytical model is loaded with anti-social values. It is on this model that the neoliberal sexual subject is based.

However, constructing this actor according to those values and classifying it as neoliberal is problematic. For example, the idea that neoliberal subjects are always rational is at odds with what Friedrich Hayek, one of the fathers of the free market in the twentieth century, states. Hayek explained that people's decisions are many times informed by limited rationality and that humans are incapable of grasping the complexities of certain process or phenomena, such as markets, because of the number of factors that are out of reach of human understanding (Stedman Jones 2012). This clearly applies to HIV prevention, where there are a range of circumstances that can interfere with the rationality of the people involved. Moreover, Hayek claimed that the fact that humans do not acknowledge this limitation is counterproductive. The question of personal responsibility is also problematic, since this concept was used way before the breakthrough of neoliberal states. In this light, this chapter will ask whether it is fruitful to regard PrEP users as *neoliberal sexual subjects*. Following this, it will provide an account of how the neoliberal sexual subject has been constructed in recent years within the academic literature.

The neoliberal adoption of the concept of personal responsibility

Margaret Thatcher, one of those responsible for promoting neoliberalism in the UK (Harry 2005:2), famously stated:

> There is no such thing as society. There are individual men and women and there are families. And no government can do anything except through people, and people must look to themselves first. It is our duty to look after ourselves and then, also, to look after our neighbours (Woman's Own, 3 October 1987).[15]

This statement illustrates the neoliberal attempt to divest the state of its responsibilities towards stated the social realm, while stressing the role of the individual and the family as key in the care of oneself and the care of those close to us. This conception of the individual as the core of various governmental matters never vanished; on the contrary, it remains one of the strategies of contemporary neoliberal governments. In July 2015, Conservative Health Secretary Jeremy Hunt delivered a speech entitled 'Personal Responsibility', in which he patently stated that 'to deliver the highest standards of health and care the people who use those services need to play their part too: personal responsibility needs to sit squarely alongside system accountability' (Gov.uk 2015). Matt Hancock, Hunt's successor as Health Secretary, appealed for healthier lifestyles, stating: 'we need to do far more to personally take responsibility for our own health" (*The Guardian* 2018). In brief, it is reasonable to assert that neoliberal governments have used the concept of *personal responsibility* to implicate citizenship in the macroeconomic aspect of public health.

However, the tenet of *personal responsibility* is not a new concept. In the United States, for example, this concept has been part of the political rhetoric since the foundation of the country. Alex Hamilton talked about personal responsibility in *The Federalist* to 'contrast the

[15] http://www.margaretthatcher.org/document/106689

powers of president and king' (Riebling 2010). In England, the concept is linked to legal terminology and its use can be traced in parliamentary literature of the nineteenth century (Great Britain 1820). The term has been used continuously throughout history, and governments have adapted it in the realm of public health to claim that 'health consumers' need to use their personal responsibility to make the correct choices.

Although neoliberal policies have a specific economic and financial goal, they require links to moral constructions of risk that act as a legitimising mechanism for the implementation of such policies. Neoliberal health institutions stigmatise people through claims regarding irresponsibility and making incorrect choices that will carry an undesirable economic load for the health services. In the context of HIV, sexual health choices are provided through prevention campaigns, but, ultimately, these choices can be classified into two categories: safe and unsafe practices. One can choose to have safe sex or unsafe sex. This reductionist approach fails to acknowledge the role of stigma and psychological factors such as shame, coping style or trauma in the HIV transmission process, while assuming a totally rational subject with no unconscious acting in a rational world free of prejudices and hierarchies other than (self-chosen) economic differences.

Is this reductionist essentialism of safe and unsafe practices a neoliberal strategy? And if it were who/what would be the agent of this strategy? There is present here the contradiction that we are all totally immersed in the discursive and material regime of neoliberalism, yet still policies are made and implemented by individuals and some people resist them to varying degrees. From a governmentality perspective, one could argue that indeed it is, since it is expected that people decide to engage in safe sex practices once they have been provided with the correct information. People are expected to calculate the risks of their practices and act responsibly. However, this focus on personal responsibility is not always as positive as one might expect.

In the context of HIV prevention, the concept of personal responsibility has had a severe structural impact and has permeated three different levels of society, namely: (i) legislative structures (Mykhalovskiy et al. 2010), (ii) AIDS service organisations, and (iii) sexual actors affected by HIV, such as those who engage in non-safe sexual practices (Adam 2005; Rangel and Adam 2014). At the legislative level, many jurisdictions require people living with HIV to inform potential sex partners of their status before engaging in sexual activity with a risk of transmission (Rangel and Adam 2014; UNAIDS 2013). The United States is the most striking case in terms of democratic liberal societies because it has the highest number of persons who have been prosecuted for HIV non-disclosure (UNAIDS 2013). In England, the law can find someone guilty of reckless HIV transmission in certain circumstances. In England, there are few cases, but it is notable that those who have been condemned belong to vulnerable and marginalised groups such as migrants or asylum seekers (Nichols and Rosengarten 2019).

Since the early 1980s, the trope of responsibility has appeared frequently in the rhetoric of the AIDS service organisations (AOS) and in gay newspapers, depicting the efforts of the gay community facing the AIDS crisis. Deborah Gould explains that these phenomena can be described 'as a rebuttal of dominant society's homophobic rhetoric about AIDS that constructed gay male sexual practices, gay culture, and the gay community as a whole as irresponsible: excessive, hedonistic, immature, and dangerous' (Gould 2007:86). Although Gould's statement referred to the United States; something similar happened in the English context. The construction of *the responsible homosexual vs the irresponsible homosexual* happened at two different levels and was shaped by two overlapping historical events. One, obviously, was the AIDS epidemic and the other was the promulgation of Section 28.

Section 28 of the Local Government Act (1988) grew out of the fear and hatred spread by the panic around AIDS as well as the general obsession with the return to "family values" under Thatcher — in turn linked to the development of neoliberal policies as well as the

tensions between individuals and families, on the one hand, and wider society, on the other. It stated that local authorities 'shall not intentionally promote homosexuality or public material with the intention of promoting homosexuality' (Local Government Act 1988). Fueled by this law and the conservative media treatment of the AIDS epidemic, hostility towards homosexuality increased considerably in England. Thus, one year after Section 28 was passed, there was a fifty per cent rise in the number of cases of prosecution of homosexual acts in England and Wales. Gay activist Peter Tatchell wrote that he found Home Office archives that revealed '1,718 convictions and cautions for gross indecency in 1989. The 2,022 recorded offences of gross indecency that year was almost as many as the 2,034 recorded in 1954, when male homosexuality was totally illegal' (*The Guardian* 23 May 2017).

During parliamentary debates regarding the passing of the law, there were constant references to what Anna Marie Smith defined as "the responsible homosexual", someone who was assimilated by the State and posed no threat to the moral order. Plummer states:

> The responsible homosexual is more than just closeted and does not just seek acceptance. He or she attempts to achieve acceptance in the terms promised by official discourse and by furthering the demonization and exclusion of dangerous gayness. The responsible homosexual therefore functions as the 'contra' force within the community; his or her presence allows right-wing politicians to speak in our name as the representatives of the true homosexuals. He or she allows them to say: 'We are not really against homosexuals per se, we are simply against the criminals, the perverts, the extremists, and so on, who happen to be homosexual'. Queer activism rightly stands against this incitement of self-surveillance, self-discipline, and assimilation. It attempts to speak to all lesbians and gays, but it does not, and should not, speak for all of us. Queer activism therefore subverts the differentiating logic of official discourse by inviting all lesbians and gays to identify with the dangerous gayness position. (Smith 1992:206)

Queer activism was largely focused on AIDS treatment and prevention and ACT UP, like its counterparts in the States, was one of the groups that was more vocal about the health crisis. However, as can be inferred from some testimonies in the National Lesbian and Gay Survey, not all gay men in England agreed with the methods of the organisations. The following testimony by a gay man born in 1923 provides a certain historical perspective about the complexities of being out and being vocal:

> I feel that there has been so much adverse publicity nowadays prompted by such organisations such as ACT UP and others by their mis-handling of the gay problem that having myself lived through the closeted years of the 50's, 60's and 70's even though it had so many drawbacks in those days, I feel more vulnerable now than I was then. The image of the homosexual (as we were known then, pre-gay) has now been changed to one of a hostile anti-heterosexual, and I personally do not like it one little bit. To achieve an integrated society of gay and hetero as is the wish of us all, will never materialise if such organisations over do the special case bit with such heavy-handed attitude. (NLGS respondent 395/3. Born in 1923. Northumberland)

This testimony refers to "so much adverse publicity", prompted by organisations such as ACT UP, as something that contributed to the vulnerability of gay men in England by highlighting the ambiguities of activism and generational conflict. This testimony counters the common wisdom that life for homosexuals before the Sexual Offences Act (1967) was gloomy and negative, and that after the decriminalisation of homosexuality being out was experienced as a great liberation for all. Despite this tension, the actions of ACT UP must be framed within the context of a health crisis wherein the government, according to the activists, had taken none of the necessary steps to tackle it. The activists themselves thought about the necessity of being responsible towards others during the AIDS epidemic. This is the second level at which the *responsible gay* was constructed in England during the 1980s, this time linked to safer sex

practices. The role of individual responsibility and its moral weight is present in the following quote from Peter Tatchell, who wrote in *AIDS: A guide to survival* in 1986:

> Choosing safe sex is thus not only a matter of individual survival, but for male homosexuals it is also a question of the collective survival of the lesbian and gay community and its achievements. Already we have lost some of the finest people in the movement -- political activists, writers, volunteer workers and just plain nobodies who nevertheless made their own unsung contribution to gay freedom by living their lives with pride and dignity. Most of these people contracted the virus long before the dangers were fully understood and publicised. They share no blame. But it is a different story for others who today continue to take risks despite the known dangers? For in this AIDS threatened era, playing dangerously-- the refusal to take care of oneself or others--is a new form of self-oppression (Tatchell 1986:41)

Tatchell's words are worthy of analysis for two reasons. First, they echo(ed) the thoughts of many regarding HIV prevention: self-care is key to preserving the community. This is an argument that is still current in HIV prevention and that is repeated in many of the PrEP users' testimonies, as will be shown later. In relation to this preoccupation with the community, Simon Watney (1988) advised of the importance of erotic education about safer sex to link the public with the private sphere; an education that needed to be situated outside of the context of guilt and fear. He continued by saying that a gay identity should now — in the late 1980s — mean safer sex. In this context in which gay identity and community were strongly linked to safe sex, it is possible to understand the blame that Tatchell placed on those who played dangerously, which he characterised as a new form of self-oppression. But, with these words, Tatchell was creating a divide between the responsible gay and the irresponsible gay within the HIV/AIDS prevention realm, while failing to recognise the role of psychological factors in HIV transmission. Watney's approach seems a bit more tolerant since he advocated for a context free of guilt and fear. But this is not without logic. In a context in which there is no

cure, vaccine, or effective treatment, it seems appropriate that health polices, and health discourses, focus on the rights and wrongs of individuals (Crawford 1994; Dodds 2002).

In conclusion, it is a fact that there is an ongoing presence of discourses on "personal responsibility" in England since Thatcher's government. These discourses differ from older discourses on responsibility in the explicit connection that they have with macroeconomic aspects, and that has produced different subjectivities in the area of HIV prevention. Moreover, the divide between the responsible and the irresponsible sexual health actor has been produced not only by the discourse of politicians at the highest levels, but also by grassroots organisations and activists. As such, I propose to look at personal testimonies by gay men who were affected by the discourses on personal responsibility during the era before antiretroviral medication as a way to trace the origins of these discourses on HIV/AIDS prevention in England.

Testimonies on personal responsibility before antiretroviral medication: 'those we love'

As explained in the methods section, the National Lesbian and Gay Survey (NLGS) is an exceptional source for the testimonies and opinions of gay and lesbian people on topics affecting them. The issue of personal responsibility features as a central theme in many of the participants' responses, and it was understood, in general terms, as a necessary tool to counteract the epidemic while promoting the idea of the gay community as an instrument for health promotion. The following testimony from a 34-year-old man living in Huddersfield in 1986 is a response to the questions that were previously introduced. After explaining that he was unadventurous in terms of sex practices, he focused on the issue of responsibility and, more specifically, on who is accountable for people's health:

> I suppose for myself, I am a conservative on such matters, but that doesn't mean I assume that others will want that for themselves, however, I cannot agree with the pseudo -Marxist "AIDS is all about society and there is no role for personal

responsibility".

> As a liberal, I believe gay liberation is about individual self- awareness and independent thought and action is most fundamental, and that must include taking ultimate responsibility for ourselves and those we love. (NLGS respondent 367)

Before analyzing this comment, I want to point out to the confusion that the term liberal often brings about. When, for example, historian Virginia Berridge talks about the liberal response by the Thatcher's government to the AIDS Epidemic in 1982, she refers 'to the way it is commonly used in discussing social policy changes - for example the changes of the 60s around abortion, homosexuality, availability of contraception etc.' (Berridge personal communication). These were socially liberal changes. These were not liberal changes related to economic policy. Returning to the testimony, this person identified as liberal in a more economic and political way, but also in favour of gay liberation. His testimony is consistent with Thatcher's critical words towards those who demanded that the government take responsibility for the health of the governed. Thus, it somehow echoes the language of neoliberal policies that incorporates a moral component in the shape of personal responsibility. But, was this testimony a neoliberal approach to HIV prevention? It seems that the critique of the 'pseudo Marxist' approach is less an embrace of neoliberalism than a plea for a more nuanced position that acknowledges a dialectic between the individual and society.

As stated above, the personal responsibility rhetoric precedes neoliberal ideology, and what makes personal responsibility a neoliberal feature is not the language itself, but how this language is deployed to attain its purpose. In the context of HIV prevention, what makes personal responsibility neoliberal is the interest of the government in making the role of the individual dominant over the community, or over the public health services: 'no governments can do anything except through people, and people must look to themselves first' (Thatcher 1987). Personal responsibility, then, cannot by itself, be understood as a neoliberal feature, as

is often understood in the academic context around HIV prevention and treatment. It is how the term is deployed and with what purpose that makes it neoliberal.

There is a need to be carefully critical with this concept and its use. In this sense, the production of HIV education by activist and AIDS organisations in the 1980s was strongly shaped by the concept of individual responsibility, and it was not until the 1990s that material on HIV education started talking about shared responsibilities (Dodds 2002). Coming back to the analysis of the previous testimony, it is reasonable to state that the respondent's words echo HIV prevention discourses that were predominant in the 1980s in England. It is also necessary to acknowledge the link between the care of the self and the care of the community, the care of "those we love". The care of "those we love" needs to be contextualised at a time when acquiring HIV was almost always interpreted as a death sentence. In that setting, strategies that involved personal responsibility were deemed imperative for the survival of the gay community. But the notion of the gay community is an ambiguous one. The following testimony explores the intersection of the gay community and personal responsibility:

> As for the gay community itself, well, the real problem is that it is not a community and the organised part of it is merely the tip of an enormous, concealed iceberg. Nevertheless, all the signs are that gay men have reacted to AIDS fairly responsible [sic], though without any real encouragement from society in general. There are limits to what we can do, and in any case many of us will always feel that to renounce a full expression of our love is too high a price to pay for safety. I am not sure that this is so wrong. Death after all stalks us at every turn, though modern societies do their damnedest to forget that fact. (NLGS respondent 183)

There is a clear recognition of the role of gay men in acting responsibly in the face of the epidemic, just as there is a recognition of the difficulties that acting responsibly entails. The text also suggests that there is a tension between what is asked of the gay population and what gay men can do in terms of prevention. Moreover, this testimony calls into question the idea

of the gay community, understood as a section of the population that is characterised simply by being gay and a feeling of fraternity and mutual care. His reference to the 'organised part' of the community has to do with the concept of community used in the promotion of sexual health in England, which has often been a controversial issue among some of the gay population, as explained below:

> Beneath the rhetoric of a community united on a common path to collective empowerment, there is in fact a hierarchy of roles which, even at its simplest, has four groupings: the funding body, the paid HIV prevention workers and the volunteers they manage, the visible clients for interventions (drop-in service users and group-work participants) and the wider community who will be addressed by media campaigns. (Russell 2006:147)

This is a more tangible and realistic definition of what the term community actually means when applied to the field of HIV prevention. Thus, this complex community acts as a kind of Foucauldian *dispositif*, in which various administrative, institutional and knowledge production structures interact with each other, maintaining a sort of (bio)power over the gay population. In this sense, power is exercised by producing HIV prevention knowledge while appealing to the personal responsibility of gay men. But this over-individualistic approach has resulted many times in victim-blaming instead of collective empowerment. In fact, the idea of the irresponsible gay *vs* the responsible gay of the 1980s permeated the mentality of many. In these terms it is expressed by a gay man born in Dorset in 1926 for the LGNS:

> In so far as there is truly a gay community it has done a great deal to educate itself, but a lot of gays do not belong to that community (and many of those who do persist in running grave risks for themselves and others). There should be much more publicity (e.g. in public toilets). (NLGS respondent 282)

This testimony reveals, on the one hand, the limitations of applying the concept of community to all those who define themselves as gay or those who have sex with other men. As the

testimony suggests, many gay men have no contact with other men outside of sexual encounters, which constitutes a barrier for accessing HIV prevention information. This is well known by HIV organisations, which use community outreach strategies to reach this population. On the other hand, there is a clear departure between the 'responsible' gay men who have made a great effort to educate themselves, and those who "persist in taking serious risks to themselves and others". In reference to the concept of "community" I consider it necessary to understand the ambiguity of this term. Many of the men interviewed in this project concluded that community was 'the scene', the venues where gay men can meet. Two non-white participants also commented on how community is white and how that community in itself represents a barrier to access to information for many other non-white men. I will talk more about this in the last chapter of this thesis when talking about prefigurative politics and race. However, as can be inferred from my previous comments, community is a complex term that has been deployed with multiple meanings and perceived, variously, as non-existent or as being key to the development of gay identities.

To conclude this section, it is necessary to take into account the fact that during the early years of the epidemic, and long before the onset of antiretroviral therapies, HIV was perceived as a very grave threat, not only to the lives of those who contracted it, but also to the progress that had been made in terms of gay rights and inclusion. In this context, a clear division was produced between the responsible gay citizen who was educated and acted in accordance with the postulates of HIV organisations in the field of safe sex, and the "irresponsible" gay man who took risks, endangering his life, the lives of those who had sex with him and even the community's life. This latter perception of some gay men as irresponsible is clearly a consequence of overly individualistic understandings of personal responsibility as a result, to some extent, of many HIV and AIDS prevention campaigns that were carried out during the 1980s. However, considering this division as purely neoliberal is wrong, since the economic

dimension of personal responsibility is absent. Neoliberalism is characterised by the 'economization of everything and every sphere' (Brown 2015:40), and the use of the tenet of personal responsibility by neoliberal governments is nothing more than the/an operational element for the economisation of healthcare. In the case of HIV prevention, before the appearance of effective antiretroviral treatment, the morals of personal responsibility were concerned with blaming those who would not engage in safe sex and contributed to creating a divide between HIV positive gay men and HIV negative gay men. But, in the reasoning of those who blamed those who did not engage in safe practices, there were no allusions to the financial consequences that such practices might carry but, rather, to the mere sexual practices of gay men.

The problematic of constructing the PrEP users as a neoliberal sexual actor

For some time now, within the study of bareback practices and HIV prevention, the concept of the neoliberal sexual actor/subject has been deployed as a sort of analytical tool that has served to interpret sexual behaviors in "economic" terms. This concept of the neoliberal actor/subject has proven popular and has been widely accepted in the academic literature. Following an introduction to its use by academics, I will provide an analysis of the problematic use of the term neoliberal sexual actor in that literature. Foucault explained that American neoliberals began to apply this analytical framework 'to reveal in non-economic processes, relations, and behavior a number of intelligible relations which otherwise would not have appeared as such—a sort of economic analysis of the non-economic' (Foucault 2008:243). The term "neoliberal sexual actor" was first coined by Barry D. Adam in a qualitative study based in Toronto that examined 'discourses employed by gay and bisexual men who regularly practice unprotected sex with new partners, and for whom protected sex occurs primarily at the initiative of a partner' (Adam 2005:333). A decade later, the concept of homo oeconomicus was used in the same fashion to that of the neoliberal sexual actor in a paper that examined 'the presence of

neoliberal ideology in the narratives and subjectivities as it relates to HIV prevention in the lives of young gay and bisexual men living in New York City' (Siconolfi et all. 2015:554). As will be explained in more depth later, other papers dealt with this concept in a different way, using the concept as the product of HIV/AIDS knowledge producers, which I consider a more productive approach.

In a sense, using the figures of the neoliberal sexual subject or the homo oeconomicus is productive insofar as it allows us to perceive certain aspects of relationships and behaviors that otherwise would remain invisible to economic analysis. This is mostly what the lens of neoliberal analysis can offer and not without risk, since it is necessary to be careful not to confuse the neoliberal analysis of the actions of a subject with a 'proper' neoliberal subject. Ultimately, what the neoliberal analysis does is to *neoliberalise* the object/subject of its analysis. The neoliberal subject is the product of the neoliberal analysis; or, even better, the neoliberal subject is just another analytical tool to make behaviors intelligible in economic terms. Things become muddled when the grid of homo oeconomicus is applied to the study of behaviors that are not purely economic. And, in this sense, we must be extremely cautious with the way we identify people and facts. Condemnatory morals tend to mix with economic language when applied to sexual actors. To support this, I will consider some problematic aspects of this type of literature, as well as some of its advantages.

The first article that configured the neoliberal sex actor characterised some HIV-positive barebakers as neoliberal sexual subjects who deployed the same discourses on personal responsibility as HIV prevention speeches to justify a potential HIV transmission. The following quotes in a study by Barry D. Adam problematise the notion of the sexual neoliberal subject, represented as a human calculator in a commodified landscape of sexual opportunities and HIV prevention options:

> The neoliberal view constructs human actors as rational, adult, contract-making individuals in a free market of options. It does not account for the much more complex motivators and vulnerabilities that characterize real human interaction and it denies the vulnerabilities, emotions, and tough dilemmas faced by people in their everyday lives. In terms of this study, the rationale advanced for unprotected sex by barebackers denies such circumstances and dilemmas that go into unprotected sex as a partner's erectile difficulties, momentary lapses and trade-offs, personal turmoil and depression, disclosure and intuiting safety, and indeed love (Adam 2006).
>
> It is especially noteworthy that virtually none of the men endorsing bareback ideology think of themselves as opposed to the message of ASOs,[16] but rather repeat basic propositions of the safe sex message as the warrant for their own practices, for example, that the responsibility for preventing HIV infection is a question of protecting oneself, or that one should treat every new sexual partner as HIV positive (Ibid.)

In the analysis of the testimonies of the barebackers, the author does not apply the concept of parity. If the barebackers' justifications for engaging in condomless sex fit within the neoliberal rhetoric by denying potential partners' erectile difficulties, momentary lapses and trade off, personal turmoil and depression etc., the article does not take into consideration that the barebacker might go into unsafe sex for the very same reasons. In this sense, the use of the concept of the neoliberal sexual subject has the purpose of morally criticizing HIV positive barebackers. A factor that should be considered in the analysis of the data is the fact that interviews were conducted "in private interview rooms provided by Toronto's leading ASO located in the city's ''gay village'' in 2002 and 2003" (Adam 2005). If as the author later states, 'ASOs as hybrid institutions of civil society and government, acted as agents of

[16] AIDS Services Organisations: non-governmental organizations that provide services related to the prevention and treatment of HIV/AIDS.

"responsibilisation" especially for gay and bisexual men', it would be sensible to consider that participants' responses were shaped by the environment in which the interviews were conducted. As has been discussed, 'the interview site itself embodies and constitutes multiple scales of spatial relations and meaning, which construct the power and positionality of participants in relation to the people, places, and interactions discussed in the interview' (Elwood and Martin 2004:649). Therefore, it makes sense that participants reproduced the ASO's discourses of responsibilisation in their favour instead of providing a *mea culpa* confession.

Moreover, although some of the barebackers interviewed for that study did disclose their HIV status, the article does not acknowledge this as something positive and valuable. Disclosing serological status has been recognised as a difficult process that can bring further stigmatisation and rejection (Wolitsky et al. 2003). In this sense, the study did not consider the penal legislation that condemns HIV positive men for not disclosing their status before having a sexual encounter. This is true for Canada, where the interview took place - a country that has enforced to a certain degree such legislation with a considerable number of cases ending in conviction (O'Byrne 2012). As pointed out above, this kind of legislation places the responsibility for the virus transmission on HIV positive people while reinforcing their stigmatisation. This has been largely criticised by HIV/AIDS activists and within academia (Weait 2007; Dodds et al. 2009; Nichols and Rosengarten 2019)

What I suggest is that this sexual actor is not neoliberal, but neoliberalised in two dimensions. The first dimension is that some authors try to apply the neoliberal grid to understand sexual behaviour. The second is that, as is often the case in both the academic context and vernacular language, the term neoliberal is loaded with moral criticism, and this cannot be obviated. In other words, the term neoliberal is matched with concepts such as

individualism, competition and self-investment, terms far removed from brotherhood, solidarity or investment in the community. Consider the following excerpt:

> Then there are risk calculators who explicitly employ neoliberal rhetoric of responsibility to justify practices that heighten risk. “Barebackers,” that is those who have chosen consistently to abandon safe sex, have been constructed as ostensible rebels or deviants beset by too much “AIDS optimism,” “condom fatigue,” or safe sex “relapse.” Yet interviews with self-professed barebackers reveal, not so much rebellion or transgression as, something more prosaic and more consistent with the discourses of government and capital. Not only does the responsibilization message resonate throughout their own accounts but the larger language of neoliberalism does as well, of which responsibility talk is a part. (Adam 2005)

I find it problematic to define the subjects of a qualitative study through a synecdoche (“risk calculator”), since by defining a whole person by a specific part, the nuances of the experiences tend to disappear, apart from the potential stigmatisation that such denomination involves. Moreover, Adam’s definition of neoliberal sexual actor is at odds with the idea of neoliberal governmentality, since the latter is someone who can govern themselves through self-discipline (Brown 2003). In a way, the previous quotes echo the mindset of HIV organisations who put the blame for the spread of HIV on those who do not follow HIV prevention advice.

In relation to blaming those who are deemed ungovernable subjects, it has been said that ‘the very notion of transgressive bare-backing is a product of prohibitive HIV prevention itself. Transgressive bare-backers are the disruptive participants of HIV prevention—the outcome prevention does not want to own but which is the required manifestation of the transgressive desire which retrospectively necessitates prohibition in the first place.’ (Russell, 2005:156). This statement problematises the notion that everything is neoliberal. Barebacking is not a "neoliberal" practice, and again, it is not a purely — or even necessarily a significantly — economic practice. Perhaps barebackers use the neoliberal rhetoric that has ultimately

permeated day-to-day rhetoric, but the author boldly states that the prohibition of condomless practices in England had a specific weight in the creation of the phenomenon by which "bareback" is understood as a gesture of rebellion.

In Sandet's clarification of the concept of the neoliberal sexual actor (2018), the author quotes Foucault to reiterate that 'neoliberalism is about the application of the economic grid to social phenomena' (Foucault 2008:239), but he does not address the Foucauldian question 'to what extent it is legitimate and to what extent it is fruitful, to apply the grid, the scheme and the model of homo oeconomicus not for all economic actors, but for all social actors in general ' (Ibid., p.268). I find the latter question of great interest for those working in the humanities and social sciences because of the ethical dimensions involved in the analysis of individuals' or certain populations' sexual behaviors. Regardless of this, Sandet uses Adam's concept of the neoliberal sexual actor to measure the negative effects produced by a PrEP campaign in United States. In his article, he interprets the concept of the neoliberal sexual actor as a product of HIV campaigns' neoliberal rhetoric. This is more in line with some of the views of England's prevention campaigns (Dodds 2002).

Data from this study challenges the interpretation of PrEP users in England as neoliberal health consumers or as neoliberal actors and sheds more light on the complexities of gay male sexual subjectivities in relation to PrEP practices. In opposition to constructions of PrEP users as neoliberal sexual actors or neoliberal health consumers, some interviewees characterised PrEP as a locus of activism, resistance and social transformation. The following testimony from my project exemplifies the efforts that one activist undertook in his attempts to make generic Truvada available in England:

> My primary reason for taking PrEP was to do tests on the batches we were bringing in, so I didn't take PrEP from an HIV prevention perspective. I took PrEP because I was guinea pigging the drug and then once I started it, I actually felt : this feels better, it reduces my anxiety for all the reasons I've explained before, but I also felt

> like a bit that as an activist who is advocating for the availability of something, if I had not experienced what is like to take this product then I'm not really speaking from a very authentic place, so I want to know when someone asks what are the side effects then I can say... well the side effects for me were this, rather than , " some people get side effects, some people don't". When they say things like so…mmm… the people who take PrEP use condoms less frequently, I'm able to say well I can talk about what happened to me and that makes it much more authentic. (Logan. Age 49. London)

Beyond explaining that PrEP can be used for several reasons not strictly linked to HIV prevention, the main theme that emerges from this testimony concerns the participant's need to be responsible for the information he transmits to potential PrEP users. His actions are embedded in a tradition of resistance/negotiation with pharmaceutical industries, and his notion of personal responsibility is oriented towards the collective, not towards the individual. But, even if all of the participants in my project embraced the idea that 'the responsibility for preventing HIV infection is a question of protecting oneself' (Adam 2005: 198), most also stated that taking PrEP was a form of taking care of others, and taking care of 'the community':

> I think that what taking PrEP is, […] it sends a very strong message that, we can have choices, and we can decide, and we can be fine, and we are serious about protecting ourselves and other people as well (Edward. Age 38. Brighton).

By highlighting the role of PrEP in preserving the health of gay community members,
these testimonies push back against neoliberal interpretations of health as a merely individual matter. Thus, although the concept of choice is very much part of the neoliberal rhetoric of individualism, both testimonies reveal that choices do not have to be strictly individualistic; they can be framed within a commitment to collective responsibility. Data from this study reveals, however, a variety of discourses and even tensions between them on choice and responsibility. Gay men have different concepts of the relationship between individual

choice/responsibility and collective responsibility. For example, the following testimony makes a statement about how preserving the health of other gay men through antiretrovirals is regarded as a "side effect" of PrEP:

> Question: When you talk about integrity, I understand that PrEP is also for you a way not to take care of yourself but also other people around you?
> Answer : Ultimately, it's about me because it has to be […] I can only be responsible for me, I can't be responsible for somebody else. However, what I can do is by getting tested and the rest of it, then I can make sure that if they do have something they're getting treated and therefore yes, I wouldn't pass it on before I got my test results, but at least I got tested and I made it the shortest amount of time that I could, of potentially passing something on. Yes, it is looking after your partners as well, but at the end of the day you can only really be responsible for yourself because you don't know what other people are doing and yes it will help them but again, they make their own decisions about they're the ones that take risks, and not use condoms or do what they do and I can't help them with that. All I can do is tell them if they don't know about it. If they ask me, I can say I'm on PrEP, talk about it so that potentially people might take responsibility and take that kind of responsibility for themselves as well. In the other ones then I do the testing and I hope that I don't pass something or catch it early enough not to pass it on. (Daniel. Age 50. Lichfield)

Here is an explicit recognition of responsibility as something that cannot be transferred. This way of thinking is based on the recognition that other people have a sovereign right to decide on their body and therefore responsibility cannot be interventionist: "they make their own decisions about they're the ones that take risks, and not to use condoms or do what they do and I can't help them with that". This could be interpreted as a neoliberal feature of the well-informed sexual actor who minimises risks through the biomedicalisation of desire. However, the overriding question that arises is, how can *not wanting to contract HIV* be constructed/interpreted as neoliberal? As happens in contemporary feminist and queer politics,

the language of rights and choice “my body, my choice” aligns with neoliberal discourses of individualism and choice. These movements may use the language of individualism and choice, but it does not mean they are nothing more than neoliberal discourses. It has more to do with the ways in which marginalised groups mobilise aspects of dominant language in order to make their claims in a way that they can be heard. Therefore, the term neoliberal is not always a helpful one when trying to understand gay men’s decisions regarding the use of antiretroviral medication for prevention or even their right to bareback.

Conclusion

This chapter has focused on clarifying the concept of the neoliberal sexual actor in the realm of HIV prevention. The concept, as has been shown, has been deployed to both criticise those who hold neoliberal valued themselves, but also to criticise health promoting campaigns. I believe the latter case more adequate than applying that grid to those who are subjects and objects of study of social scientists. However, and as it has been exposed, one of the issues of this concept is its closeness with what could be defined as a “liberal actor”, understanding liberal within the tradition of classic liberalism, and to complicate things more, the term neoliberalism has multiple meanings and entails different practices. Thus, neoliberalism is understood and practiced in different ways in different countries, this being one of the reasons why it is not wrong to talk about a monolithic concept of neoliberalism, and inappropriate to apply a fixed notion of a neoliberal sexual actor as general model. Regardless of these limitations, the concept has been used by researchers focusing on sexual behaviours within the social sciences, as a grid to point out problematic issues related to HIV prevention decision making processes.

An important part of this chapter has focused on explaining how the rhetoric of neoliberalism has adopted more traditional concepts of responsibility. This is a double-edged issue, since on one side neoliberal policies use this concept to divest institutional responsibility

from the state and place this responsibility on their citizens. The other edge of this issue is that the concept responsibility/responsibilisation has been issued as a proper "neoliberal|" concept and seen as something negative by some theorists. This is problematic because if on one hand it is true that people have to take responsibility for their own health in the face of most costly treatments and increasingly larger populations, on the other hand this type of policy making risks overlooking social factors linked to social inequalities and access to health information.

This chapter has also shown that the divide between responsible and irresponsible sexual actors was constructed before antiretroviral medication was effective for HIV treatment. In this sense several gay activists and other gay men had a strong stance of the necessity of gay men in adopting safe sex practices, namely using condoms. This divide was also produced by HIV prevention material released by AOSs during the 1980s, which somehow contributed to the stigmatisation of those who did not comply with the prevention recommendations largely based on an individual responsibility ethos. During the PrEP era, the idea of responsibility is linked to the changing aspects of what safe sex is now considered. Gay men who are on PrEP and who did not use condoms perceive themselves as responsible subjects, not only towards themselves, but also towards the community. There was almost no presence of the concept of responsibilisation in the participants' testimonies, which allows me to conclude that regardless of the intensification of neoliberal policies and discourses in the English system, the language of neoliberalism does not necessarily translate into economic and/or practices lacking in solidarity. In this sense the care of the self is linked to personal desires and aspirations has more to do with the governmental aspect of PrEP that, as will be seen in the following chapter, relates to what can be consider practices of freedom. Thus, the following chapter looks at the relation between practices of freedom and government within a biomedical intervention.

Chapter 6: Practices of government and practices of freedom within HIV prevention biomedical intervention

> The exercise of power consists in guiding the possibility of conduct and putting in order the possible outcome. Basically, power is less a confrontation between two adversaries or the linking of one to the other than a question of government (Foucault 1982:789).

> The question of what are true and false needs must be answered by the individuals themselves, but only in the last analysis; that is, if and when they are free to give their own answer. As long as they are kept incapable of being autonomous, as long as they are indoctrinated and manipulated (down to their very instincts), their answer to this question cannot be taken as their own (Marcuse 2007:8)

Both globally and in England, the use of antiretroviral drugs for HIV prevention has been defined as a biomedical intervention. From a public health perspective, the concept of intervention refers to creating a disruption in a situation that is considered problematic for the health of a population or a community. In this sense, tensions between public health interventions and the rights of communities and individuals are frequent (Hall 1992; Rothstein 2012; Lupton 2016), so it becomes pertinent to pay attention to the perceptions of freedom and agency of those who are targeted within this intervention. The fundamental question in this regard would be the following: considering the context of a biomedical intervention into the sexual behaviour of gay men in England, can these men be considered mere objects of such biomedical intervention? Or should they be considered subjects of these interventions, since they are supposed to have the necessary agency to choose whether to take PrEP or not?

Responding to this dilemma invariably leads us to investigate the relationship between freedom and (bio)power, specifically in the context of the biomedicalisation of the sexual behaviors of gay men in England. As explained in detail in chapter two, biomedicalisation implies an intensification of the influence of medicine in people's lives. While the field of

action of medicine becomes greater, some authors have concluded that this influence is often welcomed, since the power of medicine is not necessarily perceived as oppressive or negative (Berridge 1995; Rose 2007). In fact, one of the factors that hinders analysis of PrEP practices in terms of freedom and agency is the conception of power as a force exclusively of repression. I propose to tease out the ambiguities of power and the individual through a direct theoretical engagement with some Foucauldian theories on power.

Thus, power is often understood in terms of prohibitions or imposition, which complicates its continuity because, as Foucault suggested, the success of powerful interventions is given by their ability to mask their own mechanisms (Foucault 1990a). That is why, when power encounters the limits of impositions and prohibitions, it produces technologies of governmentality, the latter being ultimately a kind of tête-à-tête between the individual and the government. Moreover, in his theoretical development of the techne of power, Foucault hypothesised that:

> Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are always also the elements of its articulation. In other words, individuals are the vehicles of power, not its points of application (Foucault 1980:98).

The concept of governmentality has been explained in detail in the theoretical approach section, but it is necessary to remember that this type of government aligns people's wishes and desires with government objectives. Government does not require the oppression and punishment of bodies but requires techniques of self-government and self-monitoring. Moreover, Foucault is clear that for power to be exercised freedom needs to be present:

> When one defines the exercise of power as a mode of action upon the actions of others, when one characterizes these actions by the government of men by other

> men – in the broadest sense of the term – one includes an important element: freedom. Power is exercised only over free subjects, and only insofar as they are free (Foucault 1982:790).

Therefore, if agreeing with Foucault, a successful biomedical intervention would require free subjects. This kind of power 'traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression' (Foucault 1980:119). In this way Foucault defines power as an organic phenomenon that does not produce binary categories of oppressor/oppressed, repressed/repressor, dominated/dominator, but produces subjects through their own self-governance actions, motivated by their desires and aspirations and reinforced by the information produced by both the state and other subjects.

But the freedom mediated by forms of expert knowledge and discourses is, as has been stated, a regulated one. Within the context of 'the very real AIDS epidemic […] health promotion acts as a normative discipline to precipitate gay men into the arena of regulated freedom. A group that has been governed either through coercion or legislation now comes to be governed by knowledge, norm and incentive' (Keogh 2008:584). Although it is true that understandings of government include the efforts of legislative apparatuses to produce normative systems, the Foucauldian concept of government is better interpreted when applied along with the notion of regulated freedom. Again, it is important to remember that the context of this regulated freedom is an epidemic, and sometimes decisions taken on HIV prevention bring the past narratives of the epidemic to the present times, which is problematic. In this sense, the decision about taking PrEP is not based purely on a HIV prevention perspective. It has more to do with quieting the voices of the past. The next section looks at how PrEP can be interpreted as a biotechnological tool to control gay men's sexual lives and how this

interpretation has been challenged. It also aims to contribute to the debate on public health versus individual rights.

PrEP as biotechnological tool for the control of gay men

Previous studies on the acceptability of PrEP in Scotland found that 'rather than seeing TasP or PrEP as "liberating", for instance through reduced levels of infectiousness or risk of transmission, social and legal requirements of responsibility in relation to HIV risk reinforced unequal forms of biomedical self-governance' (Young, Flowers and McDaid 2015:12). This understanding of PrEP functioning as a techno-biological tool to control at-risk populations is supported by queer theorist Paul Preciado, who, by comparing the contraceptive pill to PrEP, argues in the blog *Parole de Queer* that:

> Truvada, as the pill, may not aim to improve the lives of its consumers, but optimise the docile exploitation of them, their molecular servitude, maintaining their fiction of freedom and emancipation while reinforcing the sexo-political positions of domination of normative masculinity. (Preciado 2005)

Preciado's statement equates the taking of PrEP to a disciplinary regimen in which servile bodies and molecules are exploited by what they have called elsewhere a pharmaco-pornographic regime (Preciado 2004). In his work *Testo Junkie*, Preciado explains that we live in a *pharmacopornographic* era wherein both the pharmaceutical industry and pornography act as agents of social control while achieving the 'invention of a subject and then its global reproduction' (Ibid., p.33). In his words, the term pharmacopornogaphic 'refers to the processes of a biomolecular (pharmaco) and semiotic-technical (porno) government of sexual subjectivity - Of which the pill and *Playboy* are two paradigmatic offspring' (Ibid.). Pharmacopornogaphic societies also control subjects by creating artificial sexual necessities that must be met. Parallels between the contraceptive pill and Truvada are obvious within this

pharmacopornogaphic frame. Both drugs can be defined as techno-sexual tools that create and subsequently satisfy sexual necessities while generating huge profits to the pharmaceutical industry, as much as US $3billion per year in the case of Truvada (Glazek 2013).

For this argument concerning forms of control, the following definition of governmentality is particularly relevant: 'Governmentality represents the different practices where power is not a hierarchical structure but different conventions of social control carried out by several institutions, self-regulating manners and the contemporary way of knowledge production' (Avila 2014). PrEP fits into this assemblage of social control, in which the non-positive antiretroviral subject's conduct is directed by health authorities, HIV community-based organisations and HIV prevention discourses. Through this process, the responsible therapeutic subject voluntarily engages in the self-administration of antiretroviral drugs that its body does not need, since there is no presence of HIV in it. This fact points to a socially constructed *artificial need* that is satisfied with the help of chemoprophylaxis plus the will of the responsible therapeutic subject. As described by Herbert Marcuse in *One Dimensional Man*, post-industrial societies create artificial needs that contribute to the control of individuals: 'the spontaneous reproduction of superimposed needs by the individual does not establish autonomy; it only testifies to the efficacy of the controls' (Marcuse 2007:10). Subsequently, these persons' self-disciplined bodies become what Foucault would define as *docile bodies* (Foucault 1977:138), part of the monitored/controlled population. In contrast, the irresponsible therapeutic citizen becomes part of the uncontrolled, the non-monitored population, and in so doing becomes a new form of sexual dissident, escaping from the sexual technologies of control.

However, I would argue that both Marcuse's theory of the artificial needs and Preciado's conceptualisation of PrEP practices involve a problematic understanding of discipline as a form of control, or molecular domination, while ignoring the fact that the modern

governance of populations requires the acknowledgment of practices of freedom (Vazquez-Garcia 2006:81). Preciado's disciplinary molecular model is close to that of the soldier that Foucault referred to in *Discipline and Punish*, whose body becomes docile through several disciplinary techniques (Foucault 1995). In this sense, power acts through the objectification of the body of the soldier, with little space for the soldier's agency. In the same way, Preciado's observation ignores the model of government or gay governmentality, in which there is a level of agency between those who govern and those who are governed. Also, it seems to imply that sexual desire — or at least the desire for condomless sex, whether in gay men or heterosexual couples — is artificially created. Somehow, Preciado's statement would hint at the idea that intercourse with condoms is more natural or authentic, which is a problematic idea. Preciado's statement hints to a *natural* molecular order in which antiretroviral drugs would have only the mission to prevent the fall of the immune system. But even if there were a natural system of molecular hierarchies, one cannot speak of a fiction of freedom, precisely because freedom is a sine qua non condition for molecular government to occur. Gay men are offered PrEP in various ways, and they choose to be on PrEP or not to be, if access to PrEP information and economic resources allow it. It is also challenging to refer to the lived experiences of gay men using PrEP as 'their fiction of freedom and emancipation' without discussing what these men have to say.

The following sections take into consideration the testimonies of those men. Preciado's statement falls into a monolithic analysis in which medical and sexual affective differences are elided and disregarded. The following testimony provides an important insight that helps to soften the idea of a sharp binary between oppressive governmentality and liberated individualism. I asked the following interviewee who he was at the moment of taking the pill. His response is important, not only because of what he is going to say in reference to the

tensions of feeling free and governed by a pharmacopornographic regime, but also because he begins by acknowledging the difficulties of defining oneself in relation to a pill:

> I'm struggling with the idea of who I am (long silence) because trouble is that it would be very easy for me to reel off something that I want to be who I am, but that's not necessarily in the moment who I believe I am, but I am a bit conflicted if I'm honest about it, because you know, there is a lot of different identities going on, and I don't know which one is prevalent in that very moment, because there is the identity definitely , one of the things I'm identifying with is being part of a movement of a revolution and that kind of excites me, but I don't know if that is necessarily what I'm feeling in that moment that I'm taking it, because there is something about being conflicted, there is also a part of me, that's indignant that I'm taking a chemical at all, you know, that I'm doing something, I'm putting something unnatural in my mouth, but whether that's anything to do with identity, but is a bit in a sense I feel, you know, I'm another person who's buying stuff from a pharmaceutical company, I bought into the idea that we have to take something artificial to live our lives, so there is a bit of you know, it's not, that annoys me, not enough for not to do it, but it does annoys me. (Warren. Age 54. Southeast London)

As explained in the methodology chapter, I wanted to end most of the interviews with this question since it gave participants the opportunity to define themselves in their own terms, in relation to the taking of antiretrovirals. I think the previous testimony is unquestionably sincere, since it does not reflect the common language of HIV prevention discourses. The answer speaks of a tension resulting from the taking of a pharmaco from a place of power, such as pharmaceutical companies, and the fact that it is part of something revolutionary. As mentioned above, this testimony somehow challenges the idea of a sharp binary between oppressive governmentality and individualism, since what is a stake here is a negotiation between those two standpoints.

Looking at the ways in which consumers are mobilised, Miller and Nicolas Rose (1997) criticised the argument of the false needs that cultural critics such as Herbert Marcuse put

forward in the 1960s. The authors argue that the consumer, far from being an automaton serving the interests of producers, is the subject of scrutiny whose psychological characteristics and desires must be analysed in order to align them with what is produced. People are not mere slaves to the whims of producers; therefore, it is not a question of creating false needs for potential consumers but of understanding their intimate desires and needs. The problem of personal agency is focused here on whether the potential consumer would buy the product regardless of the efforts made by marketing strategies. This way of understanding marketing fits to some extent within Mitchell Dean's definition of government in which power is not exercised along an oppressor/oppressed vertical axis, but by modifying the conduct through hypothetically free choice exercises that ultimately culminate in the production of a new subjectivity. In addition, Miller and Rose state in parallel that 'making up the subject of consumption has been a complex technical process. To understand this process, it is necessary to look beyond general shifts in cultural understanding or the imperatives of profit, and examine the ways in which the understandings of human individuality, personality and elaborate psychology by the psychological science have played a key role in the construction of consumption technologies.' (Miller and Rose 1997:2)

How does this apply to the PrEP user/consumer in terms of freedom/agency? To begin with, *the conduct of the conduct* is clearly reflected in marketing and advertising practices. Miller and Rose say that the expertise in psychology in advertising provides a site from which you can observe that more than a subject of dominating and manipulating consumers is a question of 'mobilizing them by creating connections between human passions, hopes and anxieties.' (Ibid.) Although I agree that consumers are not void subjects, 'creating connections between human passions, hopes and anxieties' is a liminal territory between manipulation and mobilisation. In this sense, I argue that the idea of a body that can repeal HIV is strong and legitimate enough to mobilise gay men around PrEP. But, if PrEP was initially targeted to

populations at risk, later strategies aimed to make PrEP accessible to anyone who wanted it. This shift represents a market-like strategy in which the imperatives of profit, which is not necessary a financial profit, goes hand in hand with the passions, hopes and anxieties of gay men.

In this sense, the success of PrEP is linked to the feeling of liberation that it provides, and this has to do, according to the testimonies provided by interviewees, with four different aspects: 1) the abandonment of the use of condom, 2) the ability to explore new sexual territories, 3) the ability to choose that PrEP confers, and 4) taking control in sexual scenarios as something linked to a feeling of liberation.

Practices of freedom: condomless sex, fear control, choices and the new sexual explorer

The following sections examine the testimonies of the interviewees that focus on practices of freedom, or what they have defined as liberating practices, in order to contrast the arguments that support control theories with the lived experiences of the participants of this study. As explained before, theories of control such as biopolitics, the pharmacopornographic regime or the Marcussian false needs do have a strong argument in challenging the agency of those who engage in PrEP practices. But, in opposition to the idea of PrEP as a techno-biological disciplinary tool, many participants in the study found PrEP practices liberating for various reasons, among which are taking control in sexual scenarios, PrEP as a fear control device and the ability to explore new types of sexual practices.

Taking control in sexual scenarios

In sexual scenarios where HIV is perceived as dangerous, losing control contributes to increased anxiety and even anguish. Thus, a feature that contributes to perceiving PrEP as liberating is the feeling of taking control of situations that previously would have been

uncontrollable. The following testimony illustrates how things can get out of control in certain sexual scenarios and the impact that antiretroviral drugs have on this type of situation:

> Actually I was starting to go for PEP quite often, because little things were happening, condoms were breaking, condoms were coming off and on one occasion I thought someone was fucking me with a condom in a sauna and then, I used to check, you know, I would be in a taking position and I checked, and there was no condom whatsoever. And that was the first time I took PEP, not PrEP, PEP. I remember being very angry with him actually and he said, well that guy, I was indicating to go into you with the condom, and the guy in front of me, because it was a threesome and the guy in front of me he nodded to say it's ok, but the guy in front of me was a total stranger. (Warren. Age 54. Southeast London)

The context described by Warren can be classified as an extreme situation in the sense that, apart from PEP, there is nothing that he can do to prevent a potential HIV infection. There was a negotiation before sex that obviously was not followed by the person who was supposed to wear the condom. The third person, who potentially could visually check whether the former used a condom or not, nodded confirming that everything was fine. But as the participant states, the person was a stranger. In situations like this one, there is a long way to go from negotiation to compliance, in which the decisions made are altered by various psychological and physical factors, such as, for example, sexual arousal (Shuper and Fisher 2008). These types of episodes, in which a condom breaks, or the serological status of the sexual partner or partners is unknown, become almost irrelevant when using PrEP. A person who is on PrEP does not really need to know what his other's sexual partners' serological status is in order to be safe.

The following testimony is by Daniel, a trans man who has an extremely intimate relation with biomedical apparatuses, meaning that he has an extensive experience of the biomedicalisation of his own body. During his interview he explained how his body went through several surgical operations and hormonal treatments to become the body he wanted.

The decision-making process is extremely elaborate, with life-long consequences. Apart from being on PrEP, he also explained that he took testosterone injections every three months. This is a clear example of how biomedical apparatuses are involved in the production of technoscientific subjectivities. It is also a good example of how biomedical interventions allow for people to take control over their lives. Daniel explains how PrEP has transformed the negotiation scenario that so often happens between gay men before a sexual encounter. These negotiations might happen online or in situ and have led to different prevention strategies such as condom use or serosorting. Jared provides an interesting insight into how PrEP is altering these dynamics in which serostatus has to be discussed prior to having sex:

> The thing is, I mean, there's all sorts of different people using that environment. There're people that don't know their status and don't get themselves checked. There're people that are very aware of their status. There're people who are positive, that are undetectable. But there's people that maybe have just had a diagnosis and haven't come to terms with it themselves. So, by asking that question[s], by going, "By the way, are you?" Then them thinking if I say yes, you're not going on to be with me, so I'll just say no, or I don't want to tell you what my status is. In a way, we're strangers. So, you don't need to do that. It takes away that. (Daniel. Age 50. Lichfield).

Thus, in opposition to theories that interpret PrEP as a technology for the control of individuals, Daniel's testimony points out how PrEP makes irrelevant conversations/negotiations on people's HIV statuses that have often shaped sexual relationships. If anything, for the interviewees, PrEP is not experienced as a technology that allows the medical apparatuses to exercise control, but rather for gay men to regain control over their sexual experiences. This is the case for those participants who mentioned that PrEP has allowed them to be in control of complex sexual situations. For instance, Errol, a young gay trans man who lives in Brighton and who has several health conditions, explains why PrEP is important for him:

> I suffer from psychosis, one of my symptoms of psychosis is hypersexuality and sometimes I might have not even been aware of how many people I slept with in one sitting. So, if I was to become unwell and have a drug-fuelled coke bender for instance, that I have been known to, more than once, and sleep with eighteen guys in about three days, I would not be able to physically count whether that sex was safe, on all of them so, for myself it was like I want to go on this [PrEP] because if I have an episode of like manic behaviour I then don't have to when i come around and I'm not as psychotic then have to deal with the prospect of me possibly having HIV, I mean, that's always gonna be that chance regardless no matter how much you take, pills and whatever. I want to put the control back in myself, for that. (Errol. Age 28. Brighton)

In his case, PrEP works as a safety net in complex sexual scenarios boosted by problematic mental health episodes. Errol explains that he wanted to be on PrEP to "put the control back" for himself. For him, taking control through PrEP is perceived as a liberatory practice:

> I'm chronically ill, I've got a lot of things wrong on me. Having the thought of having HIV on top of all the other things as well, it would completely blow my system, it would then be having to switch my medications, it would then be the thought of having a liver transplant because my body can't deal with heavy medications. I took the post exposure one once, and it made me so ill because of how strong the medication is, that if I was to go through that strength of medication on a daily basis it would completely knock me out and I wouldn't be able to move or anything. (Errol. Age 28. Brighton)

But Errol's case also points out to the complexity of sexual interactions that might include chem sex. Chem sex is the use of a certain type of recreational drugs that aid sexual disinhibition. Without denying agency to those who engage in these practices, this suggests the fact that some gay men feel self-conscious in certain sexual scenarios. These drugs, which include GBH, methamphetamine (crystal), etc., may help to increase sex drive, disinhibit people sexually and allow them to have sex for extended periods of time; but they can also lead to risky practices in the field of HIV prevention, because decision-making may be

compromised by the use of these drugs. Nevertheless, the idea of agency, individual responsibility and care of self/other is considerably complicated in the realm chem-sex. In this sense, PrEP serves as a tool to control the risk of acquiring HIV in these scenarios, as has been acknowledged by some participants.

Fear control and the ability to choose

As revealed by several participants, fear of contracting HIV is an unavoidable dimension of their sexuality. This fear can be linked to religious upbringings or to generational exposure to the AIDS media scare. In this sense, fear has deeply shaped some gay men's affective and sexual experiences. It is against this background that taking PrEP is perceived as a liberating experience, although this liberating experience is portrayed in different terms by the participants. For some, PrEP acts as a biomedical fear-control device that, at the same time, allows them to explore and choose the kind of sex that they want to have. This was addressed in the following testimonies:

> So, I went to the Vault, which is a sex club […], and it was a Thursday night, that's naked night and I was really curious, 'cause I didn't know what choices I was gonna make. I knew I fell relaxed and that felt liberating , that I didn't have to, you know, for the last few years specially with all the bareback stuff going on there was all this paranoia that somebody was going to not put the condom or other stuff. So, I just stopped enjoying sex really because there was always fear and paranoia. […]. So I found very liberating to be able to go to the Vault and know that even if the condom came off or something like that, I wouldn't have to rush off and do PEP, I was on PrEP, I was protected, but the big question in my mind was: was I gonna choose to have sex without a condom, cause I've never done that apart for the first few times in 1986. (Warren 55. Southeast London)

The remarks of this testimony on fear and paranoia exemplify the feelings of many men in this study who said that HIV was 'always there' or 'in the back of my mind', especially for those

who lived through the early AIDS years. PrEP works as a mechanism to control the fear of HIV, enabling more positive sexual experiences. In the case of the previous testimony, the interviewee makes clear the important role that antiretroviral medication plays in shaping his sex life and how antiretroviral drugs have helped him to keep healthy. This is a clear example of positive governmentality, in which the benefits of self-government through PrEP practices outweigh the negative aspects linked to biomedical intervention. In this sense, this person acts consistently in line with HIV prevention guidelines and is aware of the risks that the environment presents. The following testimonies also allude to the relationship between choice and PrEP. The first excerpt is part of his response to my question of when he knew about PrEP:

> To be honest I have less sex since I've been taking PrEP than I had before, and I don't know why that is but I .... cause you are somehow conscious of sex, because you are taking a tablet about sex every day, but I know that I certainly have less sex, I have the option it is not the biggest thing in the world whether I have sex with or without condoms, it doesn't make that much difference to my health

The second excerpt is in response to the question of whether he feels freer when taking PrEP:

> Yes. But it's interesting how it is translated into being sexually wild, because it certainly hasn't. It's lovely to have the possibility, it's lovely not to have the worry, but certainly before I was on PrEP, if I had sex without condoms, and I was mostly a bottom then, it [HIV infection] obviously was always on your mind (William. Age 58. Brighton).

Who really like condoms?

Most of the interviewees for this project also revealed that they preferred having sex without condoms and that PrEP enabled them to do so. This has the potential to create new public health challenges, such as the proliferation of other sexually transmitted diseases. The following testimony reveals both aspects and shows how condom negotiation occurs in the context of

hook-up apps:

> As I'm on PrEP I prefer not using condoms. Or when someone says: Do you like bareback? then I said yeah, I like bareback, but if someone uses that word in the first place then normally that means they do it as well. Someone who doesn't do it says: "I only play safe", so this normally you can tell by their choice of their words what words you can use to not scare them, but sometimes it doesn't matter what words you use if you are not using condoms you're probably full of chlamydia and gonorrhoea , but then you look at their profiles and you see last tested May 2017 …. Wow mine was December and before was August and before it was May, so I've been 3 times when you've only been tested once, and you are probably online every night, you have sex with guys all the time…Then I just think who's healthy, am I healthy or you are healthy, use unprotected, it's not because it's a condom, If you suck someone's dick you get stuff … so I've never seen anyone sucking a dick with a condom on… have you? No, you can't enjoy that…. It's the same with fucking. It's nicer without. (Christian. Age 31. Brighton)

This testimony illustrates how the concept of barebacking is being transformed by PrEP practices. Thus, the practice of having sex without condoms intentionally does not disrupt HIV prevention discourses when using PrEP. The risk of acquiring HIV in bareback practices now disappears, therefore, the appropriation of the term bareback by PrEP users complicates HIV prevention terminology. As I mentioned above, PrEP brought new challenges to public health, perhaps not as pressing as HIV transmission, but the rise of syphilis diagnoses from 2014 to 2018 in England (PHE 2019) attracted the attention of public health activists and clinicians. In fact, the HIV prevention organisation PrEPsters has included the prevention and treatment of syphilis in the campaign 'Long time no syphilis'. But regardless of the possibility of acquiring other sexually transmitted infections, several of the interviewees acknowledged that having penetrative sex without a condom was part of that feeling of freedom. I asked one participant if he felt freer taking PrEP:

> I totally feel free. And I'm really, genuinely surprised, because if you said that to me a few years ago, I would've just told you you are talking crap. I would have just said, well actually sex with condoms is totally fine. I don't see what the difference is, I don't think a rubber makes any difference. That's what I would've said to you. Whereas now, I have quite a different view, I actually think a rubber makes HUGE difference. I think that the spontaneity it's so much greater and I think, obviously not having the fear of condoms breaking, coming off, cause I'm not gonna use them anyway, but that fear is gone which is great, but also I do, I don't know whether is in my head or what, but I feel, cause I'm mostly bottom, but I do top as well, but as a bottom I feel that they can feel me better, I feel them better, and I like the whole, they ejaculate, I can feel that inside me, all of those things, to me are hugely important. (Warren. Age 54. Southeast London)

From this testimony it can be inferred that PrEP practices mediate personal perceptions of freedom in ways that confront previous HIV prevention discourses based on condom use. If the failure to use condoms has made these gay men ungovernable subjects, condomless sex practices mediated by antiretroviral drugs are producing governable subjects. But to be governed does not necessarily mean to be oppressed, since for governance to be effective, it requires the alignment of personal desires with the goals of that governance (Dean 1999). The goal of the governance will probably have more chance of success if it aligns with more than one personal desire of the governed population. For example, the goal of government is to keep HIV levels down, which coincides with the aspirations of gay men to remain virus free within an epidemic. Jointly, PrEP makes it possible for gay men to now have condomless sex, although this is not necessarily the government's goal. However, it aligns with the desires of many gay men. In this sense, governance seems to be far away from oppression, since gay men obtain multiple benefits from by taking PrEP. The following testimony exemplifies the alignment of personal desires and preferences with the goals of the HIV prevention assemblage.

> I feel freer, cause I never really liked condoms, cause when I used them on myself, I don't feel much, cause I'm not that sensitive and that's why I quite enjoyed after ... just feeling more and being less worried about what this could do to myself and then …Also, having sex with people who are undetectable. Before I was like yes, but definitively only with condom, I would never ever, even though that the chances are really low, but I was like no. (Christian. Age 31. Brighton)

The theme of having sex with partners of different HIV serostatus, as well as 'the kind of sex that you can have' emerged in different testimonies as a sign of the perception of freedom mediated through antiretroviral medication. Only one person in the study declared not feeling free and alluded to the risk of contracting other STIs as the reason for it. None of the participants referred to the act of self-governance by taking the pill and going through testing as something that constrains their freedom, or as a kind of discipline that made them more docile. Moreover, there was a positive relation between the practices of self-discipline and testing and the idea of self-care. Thus, the PrEP protocol of testing every three months was perceived by most participants as an advantage to their health, rather than a controlling mechanism. In other words, if PrEP is understood as a gay governance tool, participants did not consider these governance practices as coercive power but rather as a form of self-empowerment. The last section of this chapter deals with the concept of risk and the role that this concept plays in the government of the gay population along with PrEP.

Zero-risk bio-governmentalities

The neoliberal sexual actor has been characterised as a rational subject, but as has been mentioned in the previous chapter, not all neoliberal theorists agree with this perspective. Some have challenged the idea of humans being able to make correct risk calculations. In this sense, PrEP works as a tool to avoid those calculations, as is well explained by Jad George:

> I knew PrEP would work better than condoms and the reason I knew that it was like by analogy with needle sharing for people who inject drugs, ok? […] Condoms don't seem to work, well...they're not full proof. they're not very full proof, people forget them, people don't particularly like them, they fall off, they split, they do this they do that, ok. And that's because you have to be high as it were before you do your works, to use drug language, in other words you have to be horny already and because horny people make terribly terribly bad risk judgements. It's been shown. Whereas, drug users, one of the most effective HIV prevention methods there is giving clean needles to injecting drug users. Amazingly effective. In New York, the HIV rates among drug users is not higher than it is in the general population, it's? extraordinary, considering fifteen percent of them were HIV in the early 90s. And the reason for that is that prevention methods is used separately in time from the time of the exposure. The thing about PrEP is that you take it when you still are sober, in the morning, again with your cup of tea, not when you're often high on drugs in some dark club snogging with a bud, you know. That's why it works, it also works because it is biologically effective. (Jade George. Age 58. North London)

This testimony points to a key issue in HIV prevention, namely the ability of gay men to take preventive measures *during* high-risk sexual scenarios. The needle exchange analogy is accurate and how this method can be transported to the realm of sex is compelling. The fact that the preventive action takes place in time *before* risk exposure is even more appealing for sexual scenarios in which intravenous drug use happens. In this sense, PrEP seems to be a clear benefit for gay men who are exposed not only to high-risk sexual practices, but also to the risk of sharing needles.

Participants' responses to what they considered risk were strongly shaped by the idea of acceptable risk. Non-acceptable risk was largely identified with HIV, while most participants classified other sexually transmitted diseases of lesser concern than HIV since they were perceived as treatable. The following testimony clearly illustrates this perception. I asked the participant what risk meant for him:

> I think up until now, risk was basically any unprotected sex but now both with PrEP and being undetectable for HIV, then all these things make it safer. Obviously, there are other illnesses and STDs and stuff but usually, that's something you can treat. I think that's part of the trial to catch these things early enough if it does happen then. If you catch something within these three months, then it's easier to treat it instead of dragging it on for longer without knowing or something like that. So far, I did tend to get checked more often than three months. (Saul. Age 29. West London)

In accordance with that observation, condomless sex was not perceived as a risky practice, and three participants even referred to PrEP as 'miraculous'. For most participants in this study, PrEP was not perceived as a reluctant object that forced men to recognise themselves as the subjects of risk (Race 2016) or as a technology that required from them ‘a temporality of pre-emption in which the individual recognises their own risk’ (Thomann 2018:1000). In this sense while PrEP promotion discourses have a role in producing risk-related identities, for the participants in this study who took PrEP for reasons other than strictly HIV prevention, the notion of being subjects of risk was not accurate. For these participants, HIV risk is something external to them. In contrast, participants who had been prescribed PEP and then PrEP were more likely to identify themselves as having a risk-related identity.

However, all participants’ responses were shaped by the idea that PrEP acts as a technology that tends to erase non-acceptable risk from the equation. Thus, the choice of biomedical prevention strategies such as PrEP has brought about new techno-scientific subjectivities constructed through risk-management practices.

> I think for me it's about you have to understand the risks that you're putting yourself at and until you understand the risk that you're putting yourself at, you can't then make a decision about whether PrEP is right for you. It's a very personal journey is what I would say. I think you have to be very open with yourself around why you're having the sex that you're having, the amount of risk that you're exposing yourself

> to. If you want to pop a pill a day to probably save yourself from getting HIV for me, it's a bit of a no-brainer. If you're playing around, you're not using condoms, then you should be on PrEP because it's far more effective than waiting to catch HIV and most probably infecting three or four people along the way because you don't know you've got it until you go and get tested. (Sean. Age 38. Leeds)

Moreover, the above-mentioned techno-scientific subjectivities shaped by risk government include a zero-risk approach to HIV prevention. These subjectivities are mainly the product of PrEP discourses, with the dissemination of data from PrEP and TasP trials enabling this zero-risk approach and mentality to HIV prevention. Indeed, the Terrence Higgins Trust (2015) released a press note after the results of the PARTNER study were released, stating that 'effective HIV treatment means "zero" risk of transmitting virus'. Similar readings of the PROUD study reinforced the idea that the use of antiretroviral medication makes HIV transmission almost impossible: ‘We know it has efficacy. We know that, when taken, it can reduce HIV transmission risk by up to, probably 100%’ (Feustel 2015). It was noticeable that the zero-risk approach to HIV prevention has permeated the mentality of some of the participants. During the interviews, some of the participants referred to the results of these studies and the problematic nature of a zero-risk mentality:

> I think, in general, when I think of risk, I think of risk being on a scale. And I think that's why we use the word, cause that's the purpose of it. Because otherwise, and this is where I think there is a fundamental misunderstanding, that sometimes I see in the Facebook group. It's they don't understand, some people, they don't understand, this spectrum of risk, and so, they get caught up on the ..., they can't take PrEP because it is not 100%. But why is 99.999 so difficult to kind of get their heads around? I kind of have that awareness, but it's interesting because with HIV until PrEP, my cautious behaviour and my commitment to condoms was because I wanted to make the risk as tiny as I possibly could. (Warren. Age 54. Southeast London)

Sexual behaviours are also permeated by zero-risk approaches. The adoption of behavioural risk management mediated by the use of antiretroviral drugs was documented with several participants who claimed that they felt more 'at ease' with undetectable partners than with negative partners who had not tested recently. The zero-risk rhetoric is shaping the participants' processes of sexual negotiation with HIV-positive men. The following account reflects how one participant in this study perceived the role of antiretroviral drugs in breaking barriers between gay men of different serostatus:

> They know that if that person is taking PrEP it's pretty much guaranteed that it's never gonna happen because they're undetectable so their viral load is basically zero, you've got PrEP so, you are at virtually 100% protected against catching HIV [...] if someone tells me that they're HIV, I'm delighted, that's cool, and then that's fine, and next evening I'm on PrEP ... and we just take it forward from there, but I suppose that when the multidrug combination came it's a bit of game changer, and it does give that extra layer of protection for the negative person and the reassurance for the positive person that there is pretty much very little that can go wrong. (Sean. Age 38. Leeds)

Biomedical strategies, and above all PrEP, are mediating the ways in which gay men are interpreting risk and reconfiguring the landscape of sexual relationships between gay men in England. As mentioned in the previous section, many participants referred to 'the kind of sex' one can have with PrEP, referring to condomless sex, but also to sex with other people using antiretroviral drugs. The following testimony of a PrEP user reflects on this possible reconfiguration of sexual relationships in sexual scenarios that historically has been strongly shaped by differences in HIV serostatuses:

> I've always observed being positive as being part of a tribe, particularly in events like that [an international HIV conference], when you get to go to the special lounge, why shouldn't you? Also, a kind of a concept of positive guys I've known, particularly in places like Australia and the States where you would be invited to

> an event or a sex party or an orgy because you are positive and then you said: you mind if my friend comes? Oh, is he positive? No, he is negative ... Oh well, we'd rather not. The sense of being in or being out, but almost taking PrEP making it a tribe either of his own, trying to overlap with other people with antiretroviral users ... And I wonder for some PrEP using guys whether being on PrEP is the key to being into a club that they've been previously excluded from. (Logan. Age 49. London)

It is worth mentioning the fact that, according to the previous testimony, many HIV-positive men prefer to have sex with other positive men. This points to the fact that these men, far from being the imagined irresponsible, careless sexual actors, actually prefer to have sex with people to whom they cannot transmit the virus. For some participants in this study, the reconfiguration of sexual relations mediated by antiretrovirals seemed to already be a reality, while for another group it was a preference and a third group did not show preference in this regard. It is also a redefinition of community, or of communities within a community; a case of reterritorialisation of sexual communities mediated by antiretroviral regimens. In this sense, biomedicalisation perspectives argue that one of the ways in which biomedical technologies are involved in processes of identity formation has to do with the way in which 'technoscientific applications can be used to attain a previously unavailable but highly desired social identity' (Clarke et al. 2010:182). Thus, PrEP allows people to explore new sexual scenarios, including becoming part of *a club that they've been previously excluded from*.

In any case, zero-risk approaches to HIV prevention seem to be a reality that biomedical interventions are producing, and it will be important to remain alert to the implications this might bring in terms of HIV-related stigma. In particular, and as suggested in the previous testimony, PrEP may engender new forms of marginalisation based on the use of antiretroviral drugs for prevention as well as the reterritorialisation of new HIV sexual communities. Thus, if in the context of treatment as prevention, moral and normative expectations 'have the

capacity to both demarginalise and marginalise people with HIV' (Persson et al. 2016:359), in the PrEP revolution era new moral and normative expectations have the potential to marginalise HIV-negative gay men who cannot or do not want to engage with this biomedical intervention.

Conclusion

This chapter has focused on analyzing governmentality and freedom practices within the framework of a biological intervention. Governmentality must be understood as non-repressive power that acts through an assemblage of regulatory and non-regulatory actors. In this sense power is productive of knowledges and it is up to each person to engage in governmentality practices. As has been explained, governmentality practices shaped by the use of antiretroviral drugs have produced critical discourses among which Preciado's pharmapornographic regime, heir to part of Foucauldian theories and Marcuse's ideas regarding the production of false needs in post-industrial societies, stands out for the strength of its argument.

However, the molecular discipline and surveillance to which gay men are theoretically subjected is not perceived as a repressive power, but as a practice of freedom and agency, with liberatory and emancipatory effects. On this note, it is necessary to remember that this freedom has not translated in a similar way into the sex lives of all the participants in this study. For some, PrEP has allowed them to explore new types of sex, and for others, being on PrEP has made them more aware of their sexual activity and has reduced their sexual activity. Along with this, several participants discussed how the mere opportunity to be able to choose between using condom or not was by itself a liberating experience. Theorists have questioned the relationship between freedom and choice: 'The idea of personal choice effectively masks the systemic aspects of power – domination, social hierarchies, economic exploitation – by relegating to subjects the freedom to choose between different options whilst denying them any real possibility for defining or shaping those options' (Oksala 2011:117). As an author, I

find it problematic to state boldly whether my participants were free or manipulated to engage in PrEP practices. In this respect it is necessary to note two things. First, government as the art of shaping conducts should not always be considered as something negative or coercive. Second, some participants benefited from a larger number of areas of their PrEP practices. For example, some men benefited from PrEP since they were very sexually active and engaged in high risk sexual practices. This type of participant was closer to the selection criteria of clinical trials. Others, on the other hand, did not have as much sex or engage in so many high-risk practices, but PrEP worked as an anxiety remover and as a choice enabler. It is my belief that, although measuring personal benefit is a highly subjective issue, the first ones obtained more benefit from PrEP from an HIV prevention perspective than the second group.

Practices that were considered as liberatory and that I have defined as practices of freedom within an HIV prevention intervention were related to the necessity of taking control of sexual scenarios, something that can be interpreted as a shift from objects of intervention to subjects of agency. At the same time, PrEP was perceived as a practice of freedom since it allowed participants to choose between having sex with or without condoms while reducing the fear and anxiety associated with sexual encounters and potential infections. The possibility of having condomless sex was also perceived as a liberatory experience for many gay men that had, until now, followed the sex safe guidelines of HIV prevention regulatory agents. To conclude, several testimonies hint at PrEP practices being a producer of zero-risk governmentalities. For these men, risk was mostly associated with HIV and not with other sexually transmitted diseases. This means that some participants talked about having sex only with men who were using antiretroviral medication for prevention or treatment, which guaranteed close to zero risk sexual practices.

Chapter 7: PrEP implementation in England: a case for prefigurative (bio)politics

> 'May you of a better future, love without a care,' wrote the artist and film-maker Derek Jarman in his final year. It's a line that returned to me last month as I rode the Eurostar back to London with my colleagues, Marc and Phil. After meetings with sexual health activists from across Belgium, Marc took out the pill-holder he keeps in his pocket when he travels and swallowed the medication he takes every day. Doing so reminded Phil and I that we should do the same, each of us gulping down a generic formulation of a tablet called Truvada. This, as Jarman would say, is our better future.
>
> Will Nutland (*'If I can be protected against HIV, others should be' 2020*)

The quote that introduces this last analytical chapter evokes imagined futures under the shadow of an epidemic; better futures where gay men can love and have sex without the fear of HIV. With the increased biomedicalisation of HIV prevention, the sexual-affective practices of the future fit with the idea of a 'future in the present' that Jose Esteban Muñoz defended in his work on queer utopias (2009). This future in the present advocates experiencing freedom outside the homonormative parameters that echo the heteropatriarchal matrix's values. This future in the present advocates guilt-free sex and the embracing of sexuality as something connected to pleasure and not to reproduction. The futurity of the quote evokes, almost inadvertently, the practices of the past, the pre-AIDS forms of sexual and affective relationships that did not have to care about HIV. But for now, the present future is not without care, since there is not yet a functional cure for the virus, nor is there a vaccine; there is only treatment and increasingly biomedicalised prevention methods. Thus, the use of antiretroviral drugs as a transformative practice is present as the condition for 'our better future'. This is a future irremediably informed by antiretroviral drugs.

But there is more to this quote than the idea of a better future shaped by antiretroviral medication. There is also the flavor of activism. The scene, which takes place on a train, with

references travel around Europe and meetings with sexual health activists, is reminiscent of action and activism. In this sense, the subjective experience of the narrator is that of an activist who has a complex vision of the role that antiretroviral drugs play in people's lives. It is a vision that includes the implementation of PrEP, seemingly not only in England, but also on the European continent. How this vision is implemented, and how it fits within the aims of the HIV/PrEP assemblage are some of the questions posed in this chapter.

Thus, I draw on the concept of prefigurative politics, with the aim of reflecting on the ways in which PrEP response in England echoes democratic, solidary and community-based values. In other words, I want to deploy prefigurative politics as an ethical framework to think critically about some aspects of the PrEP response. Prefigurative politics is a term of anarchist origins, widespread in various activist movements, and it has been described as a mode of organisation and form of tactics that accurately reflect the envisioned future of society, 'a more egalitarian future' (Springer et al. 2012:1598). Thus, along with a critique of authority, the concept of prefiguration is a vital principle in anarchism (Ince 2012). It is not just a matter of critically analysing a phenomenon, a situation, but is also about devising new ways of acting in such situations.

Moreover, the effect that the self-administration of antiretroviral medication has over the biological processes in gay men's bodies allows for the exploration of the concept of prefigurative biopolitics, in which bodies can be interpreted as experimental territories for the articulation of imagined futures. In his study of childhood as a prefigurative form of biopolitics, Kevin Ryan states that prefigurative biopolitics is 'a mode of power that seeks to bring envisioned futures into the present' (Ryan 2018:299). If the concept of biopolitics is based on the idea of producing rules, laws and policies that aim to govern and regulate the vital processes of bodies and populations, the concept of prefigurative biopolitics could be understood as those practices that, by regulating the vital processes of the body, not only aim to have a positive

effect on the person who engages in them, but also to have a transformative reach in terms of social justice. This means that by engaging in such practices there is a contribution to the anarchist ethos of egalitarianism and solidarity.

So, from these 'future in the present' perspectives, this chapter aims to work as a closing reflection on how PrEP politics have contributed, or not, to values of egalitarianism and solidarity in the realm of HIV prevention. I will firstly explain the role of HIV narratives that envision a future free of HIV/AIDS in the implementation of PrEP in England. I will explore the problematic aspects and the limitations of such narratives, and which aspects of these narratives require further development. Then, I will focus on how PrEP clinical trials have used different protocols to prove PrEP's effectiveness and how clinical trials in England have benefited from trials in other parts of the world. I will focus in particular on clinical trials, since they represent the tensions between better futures supported by safer and more effective drugs and individuals' rights. The end of the chapter looks at how commodity activism has contributed to creating the future envisioned by some HIV activists, while also offering a critical reading of such practices.

Envisioned Futures: The 'end of AIDS' and 'post-AIDS' eras

Usually, the term *post-AIDS* refers to the era that followed the advent of the highly active antiretroviral therapy (HAART), whereby AIDS was supposedly no longer viewed as a death sentence. On a global scale, the adoption of this term is problematic, since every year there are hundreds of thousands of deaths linked to AIDS-related illnesses. Thus, in 2018, 770,000 persons died in the world of AIDS-related illnesses (UNAIDS 2019:6). It is pertinent to remember Foucault's second displacement in the analysis of power relationships regarding institutions. This displacement allows for critical thinking about the function of the institution and how institutions such as UNAIDS survive in spite of their failures. This type of death still happens in England, although on a much smaller scaler. For example, in 2018, 148 people died

of AIDS-related illnesses in England (PHE 2019). Therefore, I argue that a post-AIDS society is an imagined concept that helps to show the tension between the development and success of new forms of AIDS/HIV prevention methods and treatment, including antiretroviral drugs, and the lack of access that certain populations have to those biomedical advances.

The term 'end of AIDS' is more related to the realm of policy making, and it is widely adopted within the context of global health. As happens with narratives imagining post-AIDS societies, it is strongly linked to the role of antiretroviral medication in tackling the HIV/AIDS epidemic. This has to do with global health policy makers, who made a bold shift towards the pharmacological model in 2015, when the World Health Organization (WHO) published new guidelines endorsing 'first that ART should be initiated in everyone living with HIV at any CD4 cell count (a 'treat all' policy), and second, the use of daily oral pre-Exposure prophylaxis (PrEP) was recommended as a prevention choice for people at substantial risk of HIV infection' (WHO 2015:para.1).[17] Prior to this policy, some countries would endorse starting ART when the CD4 count was less than a certain number. This number has been gradually diminishing, and the current recommendation is, as mentioned, that anyone who is HIV positive must be on ART. This section not only examines how the *post-AIDS* and *end of AIDS* narratives have contributed to the processes of the implementation of PrEP in England, but also provides a critical perspective on how that process of implementation requires an acknowledgement of the structural problematic that antiretroviral medication cannot by itself prevent.

The imagined future aims to end the HIV epidemic by reaching the 90-90-90 goal proposed by UNAIDS. This goal is that 'by 2020, 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy' and '90% of all people receiving antiretroviral therapy will have viral

[17] https://www.who.int/hiv/topics/prep/en/

suppression' (UNAIDS 2019). In this regard, PrEP has an important role to play within the 'end of AIDS' narratives promulgated by both international organisations, such as UNAIDS, and local organisations. At the local level, the initiative Fast Track Cities was created with the goal that key cities around the word, including Brighton, London and others in England, would work together to reach the 90-90-90 goal set by UNAIDS. On 1 December 2014, Words AIDS day, mayors of cities around the word signed the declaration of Paris, which included the implementation of PrEP policies among other strategies to reach UNAIDS's goal.

Adrian Brown, chair of the Martin Fisher Foundation, a Brighton and Hove charity that works to eliminate HIV infections and HIV-related deaths by 2025, stated, on the occasion of the city being awarded fast-track-status, that 'There has never been a better time to work together Towards Zero HIV thanks to the new opportunities offered by PrEP, where at risk individuals can effectively protect themselves from acquiring HIV by taking a single tablet daily' (Brown 2014:para.5).[18] In this way, Brown linked, quite early in the process of implementation of PrEP in England, the narratives that advocate the eradication of HIV with PrEP. Within these global/local policy-making dynamics, UK Health Secretary Matt Hancock stated during the *AIDSfree* cities global forum that 'we are all part of the global solution to this global challenge. What we do locally in London, in Delhi, in Nairobi, in Maputo, in Kiev, in Atlanta, in other cities, has an impact globally', later announcing that 'today we're setting a new goal: eradicating HIV transmission in England by 2030. No new infections within the next decade. Becoming one of the first countries to reach the UN zero-infections target by 2030'.[19] From the above, it is possible to observe that politicians, together with HIV policy makers, have had a distinctive role in creating and producing this type of end of AIDS/HIV narrative.

[18] http://martinfisherfoundation.org/brighton-gets-fast-track-city-status-2/

[19] https://www.gov.uk/government/news/health-secretary-announces-goal-to-end-hiv-transmissions-by-2030

However, the success of the goals promoted by such narratives will depend on the amount of resources that the different cities can invest in these policies.

The news outlets echoed and participated in the production of these narratives. In January 2017 the media was reporting news that linked PrEP to the end of HIV in London: 'HIV *may soon be wiped out* in London after dramatic drop in new infections; *'We can finally beat this thing"* says lead clinician at capital's largest sexual health clinic' (The Independent*,* 11 January 2017). On December 2018, the same newspaper published: 'AIDSfree appeal: "There's an HIV drug with 99% success rate... now let's make it available to all"; Activists say PrEP trial has led to big fall in diagnoses and cap on funding is "criminal"' (The Independent, 11 December 2018). These headlines point to two themes, one is the drop in infections linked to PrEP, and the other is how activists denounced the lack of funding invested in the processes of PrEP implementation.

At other times, some journalists have been more critical of the end of AIDS narrative. For example, a journalist in *The Guardian* wrote that 'although sexual health campaigners are delighted at the news that the Proud trial is being expedited, the arrival of drugs to prevent HIV does not spell the end of Aids'(The Guardian, 17 October 2014). This statement clearly questions the following testimony extracted from the PROUD study documentary, which boldly positions PrEP as a decisive instrument to achieve the end of the HIV epidemic:

> The results of the PROUD Study have been described as a game changer. Not only in terms of giving us a simple, effective, well-tolerated treatment that dramatically reduces HIV transmission, it also now gives us an opportunity to truly deliver combination HIV prevention. And you start to see that if we were bold enough and brave enough to take this opportunity, that it isn't hyperbole or fantasy to think about defeating HIV in a generation (Michael Brady).[20]

[20] https://www.ctu.mrc.ac.uk/13706/13710/proud_documentary_transcript

This quote is problematic because it does not acknowledge the structural barriers that limit access to health information and resources. While it is true that PrEP adds a new element in the toolkit of HIV prevention, it is also true that having no financial resources, having ideological/cultural barriers, or not having the resources to navigate the health system, complicates access to PrEP. It is not a question of being 'bold enough and brave enough to take this opportunity' as Michael Brady suggests, but a question of acknowledging the lessons from the recent past: in the same way that condom use worked well in combination with antiretroviral treatment, it is also true that this combination prevention model stopped working, as previous testimonies in other chapters suggested and secondary data has confirmed it (McCormack 2015; Phillips et al. 2013). Adding PrEP to the previous combination strategy has been, for now, a successful intervention in terms of HIV infection reduction; but arguing that it is possible to defeat HIV in a generation without addressing the issues regarding barriers to access is misleading.

The role of prefigurative biopolitics in addressing the implementation of PrEP in England must focus on eliminating the barriers that prevent people who are at high risk of contracting HIV from having access to PrEP. In this sense, an HIV activist working in the sexual health sector explained the difficulties of outreach to black gay men and the problem of representation:

> I try to use different forms, but then I also feel like, going back to what I said about being seen, I think that's a massive thing, so because I am very comfortable in my sexuality and who I am as a person, I try to put myself in as many things as I can, so I'm always in campaigns, I'm always on TV if I can be, I'm always on the radio, I'm always... there's always pictures of me somewhere doing something, so that other gay men that they are not comfortable in their sexuality they can see themselves and think, you know, actually it is ok to be black and gay (Andy. Age 28. London).

This testimony provides a clear example of how structural barriers such as race, culture and religion are constant deterrents to HIV prevention information in England. However, although it is only fair to acknowledge that the issue of representation has been well approached by PrEP activists in their public campaigns, it is also true that the previous testimony by Michael Brady did not acknowledge the intrinsic racism that exists within the gay population in England. As the excerpt below makes clear the distinction of a white and black scene in London was clear in the 1980s. Moreover, community can be understood as a structural barrier in terms of race. The following testimony is by Percy, a black HIV/ AIDS activist who became HIV positive in 1986. During the oral history interview I asked him if he felt a sense of community in the 1980s:

> No, you know, there is a number of facts that came into. First, I was very young, and I was black and the UK at that time, still is, I mean the gay scene was overwhelmingly white and overwhelmingly white and British. The migration that we see from the European continent from Latin America from eastern Europe, did not exist in this country. It was binary, it was white English, British and black African Caribbean, that was it. So, in terms of gay community there was not a community for me. After a while of meeting black guys or being just me, I was quite confident, I found a pub and I would go there and slowly slowly slowly I would meet other black men, either through sexual partners or friends of sexual partners and they would slowly bring me in and opened this door, and I realised oh shit, there is this community of amazing black gay men. A bit crazy, a bit odd, like any community but they were there. And it was underground. It was away from the white gay world. We had our own parties, our own rules, our own functions, you know, so that was my community. The wider white gay community I dip into it through media, so weekly gay papers, 'cause I was really confidant in my gayness and that was the thing. That was the difference between me and a lot of my black gay brothers, and it's probably, it's a lot of the case now because I had the main support of my mum and I was reaffirmed in my gayness. I feel quite confident mixed with another gay men, it was never a secret for me. Or getting gay

> newspapers or knowing my get identity. So, in that sense, that's where community came from me. […]
>
> What kind of music would you listen in the black scene?
>
> Oh! In the black scene! I mean, that was different, so you know you go to the white scene and it would be high energy and disco which I love a little bit of disco, but the black scene was the music I heard at home. That's what was different, that's why we created our own spaces, yes, because we could go to gay clubs, but it was gay on your terms, this is what gay looks like, you have to like this music, you have to dress this way. And then we had our spaces, it was recreating our lives, our homes our traditions in the same way that a group of Spanish guys would too and would play some Spanish artists or have a particular food or there's a different way of doing party, and usually the way we'll do party is much more interesting than the English. Right? So that was what it was about, it was about going to spaces which were not just safe, but it was about creating an identity where you were just yourself. (Percy. Age 48. West London)

It is remarkable that in a historic moment where the feeling of gay community should have prevailed, Percy confesses that he did not share that feeling of community. He alludes to the cultural divide between the black and white population, as well as the sense of self-esteem that helped him navigate between two communities. The testimony also makes clear the strong territorialisation (DeLanda 2016) of both communities through cultural values. This gap between communities is a structural problem and determines the differences in access to health-related information. The following testimony of a PrEP user illustrates how he feels about racism in the gay community in Brighton. I asked this person what role the internet had had played in relation to his gay experiences:

> I do apps but I think they are shit. I think that's why I'm quite wary, I don't have any expectations among Grindr. I have zero expectations. I've met some really lovely people; I've met some really good friends. Sexual encounters not that frequent. The thing that I don't like about it is the you can now tell that ... it is just

> ... it’s just shit. I don’t know what is about people needing to put people in boxes. Literally, I don’t get that, like you know: 'I identify as being a man' you know, wtf... seriously? I understand but why do we feel the need to, even ethnicity, does that really matter? really? what do we feel that something that you don’t necessarily feel comfortable bringing up with someone else, what do you feel that that's ok to publicly share with everyone. I mean, I do get a lot ...the racism is disgusting in the apps. You know they look at you and they just see dark skin, and they think, they must be Indian, don’t do Indians, it's like fuck you very much...I don’t get it. And of course, everyone has our own preferences, and everyone has our own taste and that's fine, but when people put that on their profiles ‘no blacks’, ‘no Chinese’, none of this you know what? You wouldn’t put that in your window, would you? In your shop. That’s outrageous. Brighton is very white. We are very cosmopolitan, there is a huge mix of people here, but not like London where is very segregated where there is an Italian pub, or there is a Greek pub, or there is a Chinatown. Brighton is Iranians and next door to Afghani and then next door to gay. And it's fine. It’s a rich culture, a tapestry of everything, nice mix. But I think for a group of people who has been penalised and ostracised for being a minority, we are horrendous. We are horrendous human beings because we are doing exactly to people what we have encountered ourselves and we have been fighting for equality and all that stuff and for sexuality, yet we are happy to be racist. (Jim. Age 34. Brighton)

From a prefigurative biopolitics perspective, it is highly problematic that racism is rampant within the gay community and, as the participant suggests, it not only creates not a hierarchy of preferences, but supports racist discourses. Within the hierarchy of racial preferences those in the bottom of the pyramid have less power to negotiate. Moreover, race is one social determinant of health (WHO-CSDH 2008).[21] To fight these barriers PrEP activism has carried out numerous face-to-face and online actions for queer people of colour. These outreach and educational actions have also been facilitated by queer people of colour. However, for now,

[21] https://www.who.int/social_determinants/thecommission/finalreport/en/

this population continues to be the one with the least access to PrEP and the population with the highest incidence of HIV (Witzel et al. 2019). A key idea of prefigurative politics is that the work for a more equalitarian future should never be perceived as finished (Ince 2012). This idea seems to be part of the ethos of PrEP activism and part of the toolbox of HIV prevention activism in England. The idea of scrutinizing discriminatory practices needs to permeate all the aspects of the implementation of PrEP in England, including the clinical trials that have allowed for PrEP to be a successful intervention.

Clinical trials and prefigurative biopolitics

Clinical trials have played a leading role in the fight against the spread of AIDS/HIV and they are necessary for the development of new drugs. In general terms, the purpose of clinical trials is to determine the efficacy and safety of a drug for the treatment or prevention of a disease or a specific condition. The results of the trials can be used by governments, mandated bodies to decide whether to buy the drug or not, and by researchers and doctors who will decide if the drug can be used for treatment for their patients. This section looks at the ethical aspects that are key to understanding the existing power relations between those who set up a clinical trial and those who participate in it. In this regard, scientists' responsibility towards participants' welfare and safety is fundamental to clinical research, and any possible negative consequences from participation must be minimised, as ethical policies recommend.

An interest in the ethical dimensions of human experimentation can be traced to the end of the nineteenth century, although it is widely accepted that the Nuremberg Code (1949) was the first policy document providing ethical guidelines for clinical trials after Nazi experimentation on concentration camp prisoners. Following this path, The Declaration of Helsinki (1964) aimed 'to provide guidance to physicians engaged in clinical research and its main focus was the responsibilities of researchers for the protection of research subjects' (Williams 2008). Nowadays, research ethics committees act as regulatory agents that aim to

secure that, under the trial protocols, participants have all the necessary conditions to minimise their risk while maximizing the benefits of their participation. This regulation differs from country to country, but it is notorious that the design of some clinical trials does not always have as a first objective the benefit of their participants (Hemminki 2016). This is the case of some type of clinical trials such as noninferiority trials, which have been called out as plainly unethical, since participants don't obtain any benefit from participating in them (Garattini and Bertele 2007). This section's aim is to put the iPrEx trial and the PROUD trial together under the critical lens of prefigurative biopolitics. Both PrEP trials are mentioned in the introduction of the thesis, and the iPrEx trial was fundamental for the implementation of the PROUD trial in England. I will try not only to provide a critical reading of said trials, but will also propose what could be done differently, so that these trials fit within the imagined HIV 'better futures' in which not only the English population can benefit from PrEP practices.

For that purpose, the main question that will shape this section is the following: how have the clinical trials carried out in and outside of England embraced the values of prefigurative biopolitics? In answering this question, it is necessary to pay attention to the existing power dynamics of those clinical trials. Do the trials reflect solidarity and community-based values, or do they reflect commercial values? In looking for examples of clinical trials that reflect community-based values and social concerns I propose to look back to the history of AIDS and try to understand how the first community-based clinical trial occurred in New York in the early 1980s. I asked Dr. Evans about how and why he set up this type of community-based clinical trials:

> In 1983, when this was happening in the United States, clinical trials took place at hospitals, medical centres. They were specialised and they didn't have people, enough patients, they didn't have enough subjects to take part in clinical trials […]. People with a condition, in this case HIV, they come to hospitals they see the doctors and they send them [away]; it is not an easy place for recruiting people for

> clinical trials. I knew that a place where people could be found would be in the clinics, in the doctors' offices, that's where they went, but those places never do clinical trials, they're not equipped, they don't have the academic background, it's another world, and nobody thought that doctors on the street were able to do clinical trials […] That meant bringing the academy staff to the community doctors. (Dr. Evans. Age 83. Central London)

In this part of his testimony, Dr. Evans explains that, at that moment in the epidemic, there were two important factors to consider in order to set up trustworthy clinical trials. First, in order to reinforce the validity of the trial it was important to recruit enough people. Reliable clinical trials depend upon the number of participants in them, so that if the trial takes place with few participants, the results are not interpreted as conclusive. This is a limitation in terms of prefigurative politics, since the larger the group size is, the more difficult is the process of 'democratisation' or 'horizontalisation' of the trial. The second important factor was to create alliances between clinical doctors and academic doctors. The latter knew the particularities of setting up clinical trials protocols, and the former had the potential to recruit enough patients. Thus, the idea was to develop clinical trials in community settings instead of in academic medical centres. At that moment, this type of community-based trials was also based on the idea of using drugs that were already available on the market, since there was no time to wait for any kind of pharmaceutical development in terms of antiretroviral drugs. As Dr. Evans explains in the following excerpt, this type of trial had the advantage of prioritizing people's health over the companies' profits:

> […] then I became a little more suspicious of industry trials understanding the reality of business oriented for profits enterprise, their authenticity, and the thing they were doing was selling products, and I am speaking about my thinking of [he pauses] so I thought then that the motivation for industry for trials was to produce a drug they could sell basically speaking, and in terms of protecting the interest or finding something that could be of help to people with this disease without the

> notion of profits or anything like this, then we could do community, different trials that were generated without any view to making money so one could study common drugs that were available, that might been promising and not make money from them. (Dr. Evans. Age 83. Central London)

This testimony reinforces the idea that industrial clinical trials do not always have as their main concern the health of those participating in the trial, but rather the benefits to the pharmaceutical industry. There is an extensive literature on this type of industrial research conducted in Latin America, where the ethics of the trials are in conflict with the logics of business (Homedes and Ugalde 2014).

In England, AIDS community-based trials did not happen mainly because the low number of people affected by the virus at the beginning of the epidemic would have made clinical trials unfeasible. But the effect of this type of community-based clinical trial, in which the power dynamics between the stakeholders does not have an exclusively top-down approach, has been replicated around the world in an attempt to recruit participants who initially would have been suspicious or reticent to participate in industrial trials. By1990, the United States had run hundreds of clinical trials while in Britain only the Concorde trial had been set up and most of the budget for the research of the condition was dedicated to the research of a vaccine (Watney 1994).

Intersections of activism, clinical trials and politics

In this section I want to point out three aspects in which the role of activism in HIV clinical trials has been important: 1) activists influencing scientific aspects of clinical trials, 2) the role of activists in speeding up clinical trials, and 3) the disruption of clinical trials that have been considered unethical.

Regarding the scientific design of protocols, American HIV/AIDS activist Martin Delaney proposed the use of CD4 count as a surrogate marker for deaths or ‘body counts’, the

latter being one of the parameters measuring the lack of efficacy of HIV drugs. CD4 are cells that reflect someone's immune system status and a low number of such cells is linked to opportunistic AIDS-related illnesses. Delaney stated that the future we all envisioned would not be real if scientists did not change the biological markers in their clinical trials (Epstein, 1997). When biological markers or endpoints for the results of a clinical trial consist of counting the number of deaths, the theoretical political model is closer to necropolitics than biopolitics, and much further from prefigurative biopolitics. It might be necessary to point out necropolitics is a theoretical concept coined by philosopher Achille Mbembe (2003) and refers to the way in which is determined what individuals are more and less dispensable than others. The role of activists in shaping clinical trials' protocols has been largely acknowledged, particularly in the United States (Gould 2009:294).

The work of activists in United States and their demands on expanding the access to experimental drugs was echoed by HIV/AIDS activists in England. Thus, Simon Watney wrote: 'We should remember that AZT, which is manufactured here in England, had been available to more than 3000 people in the USA, but only 12 in the whole of the UK, although it is soon to be more available on the NHS, though not thanks to any campaigning from the Trust (NHS)' (1994:36). However, the role of AIDS activism is open to question. In the face of death, activists demanded an acceleration of the trials and to take parts in clinical trials of drugs that represented hope. In hindsight, this was a problematic demand, since there was no scientific argument that could support it; it was hopelessness that moved activists to demand drugs that had not been properly tested. This would be the case of the Concorde Trial in England that aimed to test the effectiveness of AZT.

In England, the prospect of an epidemic of the same menacing dimensions as in the United States brought the issue of clinical trials and access to AZT into the area of political debate. The following excerpt, which is part of a debate in the House of Commons regarding

the implementation of the Concorde trial, is an example of how politicians got involved in the development of clinical trials for antiretroviral drugs in England. As was mentioned in the introduction to this thesis, this trial was sponsored by Britain's Medical Research Council in cooperation with the French *Agence Nationale de Recherches sur le SIDA* and aimed to assess the efficacy of AZT in delaying the onset of AIDS in asymptomatic HIV positive individuals. Conservative MP Roger Sims questioned the availability of AZT in the country:

> Q. Is my right hon. Friend aware that the relatively brief trials in the United States on the drug AZT suggest that although it may not be a cure it could delay the progress of this disease? Is he further aware that the Wellcome Foundation is putting a great deal of resources into work on this drug and that the development work is four times ahead of normal progress with a drug of this character? Will my right hon. Friend also confirm that, despite reports to the contrary, adequate quantities of this drug are now available for clinical trials in this country and that the reason for any delay in setting up such trials is to ensure that the trials are properly set up, and not because of any shortage of the drug?
>
> A. Mr Norman Fowler Secretary of State for Health and Social Security. Yes, I think that I can confirm my hon. Friend's last point. Clinical trials are being set up in the United Kingdom. As my hon. Friend said, AZT is not a cure for AIDS, although in some cases it can prolong life and alleviate the symptoms in some patients (HC Deb, 26 November 1986)[22]

On one hand, the previous dialogue illustrates how the history of HIV/AIDS in England has often looked at United States' developments in terms of treatment and prevention. This is also true in the case of PrEP, as several participants in this study refer to friends in the United States using PrEP and it was the approval of the FDA of Truvada for PrEP that paved the path for the PROUD trial in England. However, it is necessary to specify that the Concorde trial was a

[22] https://www.theyworkforyou.com/debates/?id=1986-11-25a.123.2

search to find answers regarding the American guidelines on AZT use. On the other hand, the previous quote reflects the lack of awareness, or at least the lack of relevance, of the ethical aspect of clinical trials in political debates. Political debates in England around clinical trials have focused on how to find or who is accountable for the material resources and have paid little attention to the ethical aspects. To illustrate this, in 2016 a debate in Parliament also focussed on the cost-effectiveness of Truvada for PrEP. During the debate, Jane Ellison, who was at the time under-Secretary of State for Health, explained that after the PROUD trial further evidence was required. The National Institute for Health and Care Excellence (NICE) was in charge of producing a report that looked at effectiveness, safety, patient factors and resource implications. Following this report, the government set the IMPACT trial with the goal of assessing the cost-effectiveness of PrEP as biomedical intervention.

Coming back to the Concorde trial, where lives were at stake, it would have been good to include a patient/participant/activist committee. Initially, the trial brought into question the validity of CD4 count as marker of the success/failure of the drug or as an indicator for AIDS progression and included the number of deceases as a marker for the failure of the therapy. At the end, their own report of the trial highlighted the value of the CD4 as a valuable marker. It has been speculated that AZT in fact contributed to the deaths of many who took the drug because of its toxicity; therefore, progression of the disease should have been enough of a marker to stop participation on the trial. The following testimony illustrates this situation:

> Later on when I read the results of the Concorde trial and all that it did was to buy a couple of months of life perhaps, I thought I was erm, possibly that may have been the correct decision, taken for the wrong reasons, but ... and years later in 1998, at the Geneva AIDS World Conference, the first AIDS world's conference that I ever went to, my Saint Mary's Doctor, who I hadn't seen for years, came up to me and said, you know what? at Concorde you were right and I was wrong, 'cause he kept on trying to persuade me to take AZT and I wouldn't do it, even if

> my CD4 were going down and down and down. (Jad George. Age 58. North London)

This testimony is in line with the trial result article in which the authors explain that, due to clinicians' and participants' pressure, they had to "unblind" the trial, so that patients could decide whether to adopt any other type of treatment. The question, then, is was it necessary to set up an AZT clinical trial when there was a clear opposition to the drug coming from patients and activists? On one side, the response is that the clinical trial put on paper what many have already experienced, namely that AZT was not the drug that was going to save people's lives. On the other side, the inevitable question is whether those who died during the trial may have survived if they had not taken the drug.

The motto 'getting drugs into bodies' that ACT UP popularised, with the goal of providing fast access to drugs to people who needed it, represents a key issue of prefigurative biopolitics. As happened in the United States, the debate about accessing experimental drugs was characterised by tensions between two standpoints: those who just wanted to accelerate that process of getting drugs into bodies, on one hand, and those who advocated doing work to break down barriers to health services, information, etc., on the other (Gould 2012). The future of HIV cannot only be shaped by access to AIDS drugs; to be transformative everyone needs to have access to relevant information and proper HIV care.

The last aspect that touches on HIV trials and activism has to do with activists stopping clinical trials. In this sense, various PrEP clinical trials were halted before the iPrEX trial. For example, in 2004, activists in Cambodia pressured the first minister to stop a PrEP trial with sex workers. Among the reasons to stop the trial they cited 'inadequate prevention counselling by the study investigators, a lack of pre- and post- test HIV counselling, and the non-provision of medical services and insurance for those who seroconverted during the study or experience adverse events related to the trial drug' (Singh and Mills 2005:0824). In 2005, another PrEP

trial in Cameroon was stopped by the Minister of Public Health when 'activists alleged that the Family Health International (FHI) investigators intentionally allowed participants to become infected and provided inadequate counselling by having only five counsellors for 400 participants' (Ibid., p.0825). These are clear cases of malpractice that led some to ask whether participants in developing countries were considered to have fewer rights than those in England.

Vaccine Clinical trials for HIV prevention and the problem of the disposable subject

In the case of clinical trials for HIV prevention, it seems obvious that using a marker such as "numbers of deceased" should be out of the equation since the goal is to figure the efficacy of a drug to prevent HIV and not to treat it. However, the question here is: are some subjects in clinical trials more valuable than others? Are some bodies more disposable than others? The following excerpt from a research document for the House of Commons from 1995 provides material for discussion:

> While HIV/AIDS remains incurable, prevention is the best strategy. Human behaviour is difficult and slow to change and subject to cultural pressures. A vaccine would be the most desired option, but research so far has been disappointing. The decision of the USA not to go ahead with widespread clinical trials of two vaccines (both based on components of HIV's outer coat) on the grounds of their dubious efficacy has left other nations with a dilemma. The WHO has since permitted trials of these same vaccines in developing countries should their governments wish it. Trials of one of the vaccines began in Thailand early in 1995, though some scientific and ethical concerns remain (Cushion 1995:5).

In this case governments from some developing countries required permission for the implementation of vaccination clinical trials regardless of 'their dubious efficacy', arguing that the impact of the pandemic in their countries was stronger than in the United States (Cushion 1995). However, it is difficult to understand on what grounds the WHO gave the green light

for it, knowing that there were numerous reservations about the efficacy and safety of the vaccines. In fact, the MRC developed guidelines on the technical and ethical aspects of vaccination clinical trials that were used for consultation at the World Health Organisation, but the same MRC acknowledged that it would take years for clinical trials to take place in England (Cope 1990). In fact, they never took place. As has recently been revealed in the current COVID-19 pandemic, when a doctor in France suggested conducting a vaccine clinical trial in Africa, there is a mentality that developing countries have a more apt scenario for guinea pigging than developed countries (BBC 2020). [23]

The issue of how HIV vaccine trials were implemented shares the same ethical problems as the first PrEP clinical trials. Thus, the aforementioned WHO document specifies that clinical trials with vaccines must adhere to the three basic ethical principles of biomedical research in humans. These three principles are beneficence, justice and autonomy (WHO 1989). These three principles can serve as a moral compass; however, their interpretation is often subjective. Thus, the principle of beneficence implies the obligation that the participants in the trial do not suffer damages and that, for them, the risks to be taken are minimised. The principle of justice requires that the risks and benefits that may be derived from the clinical trial be shared. The principle of autonomy refers to the fact that participants in clinical trials are considered autonomous subjects with the ability to choose. This principle is especially problematic since it depends to a great extent, not only on the personal situations of the participants, but also on the degree of involvement of the medical personnel in the clinical trial. A clear example of this is the testimony of the previous section in which the doctor tried to persuade the patient to continue in the Concorde trial. This could have had very serious consequences for the participant. In addition, this type of action not only works against the

[23] https://www.bbc.co.uk/news/world-europe-52151722

autonomy of the participant, but also against the principle of justice, since it involves the patient taking more risks than necessary. Again, what this section reinforces is the idea that some participants in certain countries have fewer rights than other participants in developed countries.

The iPrEx trial as the base for the success of the PROUD trial

As mentioned in the introduction to this thesis, the iPrEx trial was conducted at eleven sites in six different countries including Peru, Ecuador, Brazil, Thailand, South Africa and the United States, with an uneven distribution of participants. Thus, only 9 percent of the participants came from the Unites States, while 56 percent came from Peru (Grant et al. 2010). The trial aimed to ascertain the level of protection against HIV when using Truvada for PrEP. The results of the trial stated that a daily dose of Truvada 'provided 44% additional protection from HIV among men or transgender women who also received a comprehensive package of prevention services' (Ibid., p.2597). The authors of the trial also acknowledged that the protection level of the drug was less than initially imagined. Regardless of the poor results, the FDA approved Truvada for PrEP, which contributed to the making of the PROUD trial in England. This section compares and contrasts both trials and looks at the problematic of both when analysed together.

Regardless of the well-defined ethical considerations that the iPrEX trial protocol included, I argue that the different socio/cultural stratums of the subjects in both trials were key for the failure of the iPrEx trial and the success of the PROUD trial, and that this difference raises ethical questions. Among these ethical issues, I include the problem of the participants' poor adherence to a drug within the iPrEx trial, in contrast to the good level of adherence in the PROUD trial. The success of PrEP depends largely on the level of adherence of an individual to the treatment. This could be said of all medical treatments, but in the case of HIV

drugs, this is more important, since an incorrect administration of the drug could lead to drug resistance. In the case of PrEP, if someone fails to adhere to the treatment and, because of being exposed to HIV, acquires the virus, it is very likely that the person's body will become resistant to Truvada. This is very problematic, because resistance to a drug makes treatment for HIV more complicated. Resistance to Truvada is a particularly important issue since it is one of the most prescribed drugs for HIV treatment.

According to a systematic review on the adherence to oral PrEP, adherence is informed by several factors that include geographical location and socioeconomic conditions (Sidebottom et all. 2018). In this sense, the different clinical trials that have been developed in the world seem to have not considered these factors. In the case of the iPrEX trial, the level of the participants' education was much lower than in the PROUD trial. Thus, in the iPrEx trial 22 percent of the participants had not completed secondary school, 34 percent had completed secondary education, and 42 percent had completed post-secondary education. In the case of the PROUD trial 61 percent had a university degree and 39 percent did not. To illustrate this point, I asked one participant in the PROUD trial if he had read about the iPrEx trial. His understanding of what was at stake in the trial seemed very good:

> Yes, I did. Actually, because the efficacy is actually not that great. I went and looked at it and I read the articles about is it because of the way the study was set up and there's lots of people who actually contracted HIV and didn't even have any drug in their system? I was still left with this, "We just don't know if it is 50% effective or 80% or is it much higher?" and just going, "No one knows." It could be really good; it could be actually pretty awful, or it might be moderate. Moderate is not really great. That doesn't take away any fear in a way. It just maybe lessens the chance. (Leo. Age 40. East London)

Taking into consideration that 22 percent of the participants in the iPrEx study did not have a secondary education, two hypotheses can be made. First, that participants in the iPrEx study

did not have as good an understanding as participants in the PROUD trial. However, it is problematic to assume either people without secondary education are unable to understand fully the process of a clinical trial, nor that people with university education are. The second hypothesis is that necropolitical forces led one trial to make one group – the less educated—the more dispensable. The following testimony provides an insight into the differences in the types of people who were recruited for the different clinical trials for PrEP in different parts of the world. I asked an HIV journalist what happened in the UK for the results of the trial to be so successful:

> Firstly, they gave it to an already reasonably well-educated group of gay men who understood this. Secondly, they weren't any, what you would call perverse incentives, I think that in IPrEx if, as I said, if you were in Iquitos or Guayaquil or any of other places, and this reflected in the women's study of PrEP too in South Africa, there were lots of others reasons for joining the study, other than they give you an HIV prevention pill, [...] the women said we're joining the study because we get better health care, we didn't care about the pills, we throw them away, that was just a way to get better health care. And I think the same applies to the gay guys they did iPrEx with a sort of additional thing actually, probably the best way to meet other gay guys if you are in one of those places. (Jad George. Age 58. London)

This testimony points to different factors such as the educational level , or the lack of perverse incentives as key to understanding the different results in PrEP efficacy in PrEP trials, forty-eight percent efficacy in the iPrEx trial versus eighty-nine percent efficacy in the PROUD trial in England. This means that a considerably larger number of persons became HIV positive during the iPrEX study. For example, out of 2499 men in the iPrEx study 131 men become HIV positive during the clinical trial, whereas 10 men became HIV positive out of 481 in the PROUD study in England. This raises multiple questions about the ethical validity of doing PrEP trials in contexts where people have very challenging socio-economic conditions.

However, the previous testimony opens the door for an interesting interpretation: some women in the African trials accessing them for ulterior motives is a very good example of people with lower levels of formal education knowing exactly what they are doing and using the trials for their own ends.

Thus from a prefigurative politics standpoint, I propose that recruitment for clinical trials should target exclusively populations that a) are educated on the mechanics of clinical trials at a level that can fully understand / negotiate the complexities of clinical trials , and therefore b) have a clear notion of the risks taken, c) have a vision of the benefits that the drug can bring to his life and d)might not be driven by perverse incentives. Ideally, 'interventions should address social inequality to achieve health equity across pandemics' (Pirtle-Laster 2020), but I assume that is more feasible to recruit people who are or can be educated at certain level on clinical trials, than change the whole structure that prevents them from getting access to a good education. From a prefigurative biopolitics standpoint, the trials should aim to break down the binary between scientists and "guinea pigs" as part of the process, and give agency to the participants, by listening to their needs as well as educating them about the processes/risk. The following testimony provides a relevant insight of how education on PrEP plays a fundamental role. I asked the participant of the PROUD trial if he has stopped taking PrEP:

> Yes, I've stopped now. I think I'm thankful enough that I've been sufficient. I'm educated in PrEP and I've spent a lot of time around it and looking into it and understanding it. From both sides, from taking it and from a pharmacist's perspective and that's really helped and enabled me to be able to use PrEP and protect myself and then protect other people as well. Through that a lot of my friends have accessed PrEP as well and have been able to understand the pros and cons and how they can use it and those things. I fully recognise that, within the white, kind of well-off gay male arena in that sense, that's not unusual. There's lots of people who have that and then people who rely on that information spread

> through them. I think the benefits of PrEP will really come through [in] when we can get it into the people where you don't have those expertise in the community. We have to create those and then it's got to spread out. Making it available isn't enough, you've got to get it used and they're very different things. (Leo. Age 40. East London)

This participant explains how having a background in pharmacy helped him to start on PrEP, and he credits sharing theoretical and practical knowledge as an enabling factor for other people to engage in PrEP. He acknowledges that this type of knowledge is for now circumscribed to a certain type of demographics (educated white, well-off), and therefore peer-education seems to be relegated to that demographic that owns the expertise. He forecasts that the benefits of PrEP as an intervention will come when the barriers of that expertise are knocked down.

The different design of the trials is also a matter for ethical concern. As explained in chapter 2, the PROUD study was an open label trial, meaning that participants in both groups knew which treatment was being administered, and whether there was any participant who received placebo doses. Everybody in the trial would take generic Truvada, but one group would start taking it one year later. This group was called the deferral group. This was not the case for the iPrEx study, which was a randomised, double blind trial, meaning that participants were allocated Truvada or placebo treatment aleatorily, and nobody knew what they were taking. Seroconversions were high in both groups due to the lack of adherence, but it was predictably much higher in the placebo group. If adherence had not been an issue, a much lower number of people would have become HIV positive. Although the PROUD trial was not designed as a randomised control trial, the article that published the results justified the use of placebo in other PrEP trials by stating that if participants do not know if they are taking PrEP or placebo, then participants would not engage in riskier sexual practices, meaning more condomless sex. This shift in sexual behaviour is denominated risk compensation. The article states that risk-compensation could jeopardise the ‘biological protection conferred by PrEP and

its value as a public health intervention' (McCormack et al. 2015:54). But these hypotheses have not been confirmed after the massive used of PrEP; on the contrary PrEP has been a successful intervention in England. Moreover, the key point of PrEP as a biomedical intervention is to enable sex without condoms as a form of HIV-safe sex, as the article argues. This type of clinical trials using placebo has been historically questioned by AIDS/HIV activists (Gould 2009). Although, as mentioned above in the case of AZT, the role of activists in speeding up the approval for drugs that were not tested following strict guidelines, was problematic, in the case of PrEP this wouldn't have been the case.

Not only that, it also raises questions about the ways in which the information about the procedure of the iPrEX clinical trial was not only delivered to the participants, but also processed by the participants. The iPrEx protocol included abundant guidelines about how to deal with participants' consent, but it rather seems that the concern is about the legal actions that could be derived from the participation in the trial and not for the health and wellbeing of the participants themselves. As has been exposed in a study about clinical trials in Latin America (Homedes and Ugalde 2014), the ethical review of protocols represents a fundamental part of the authorisation process for the trial. However, this authorisation process, depending on the countries concerned, might involve demanding further information about the research protocol. The information required by 'national authorities tend(s) to be administrative, that is they are related to the presentation of documents, followed by problems of informed consents, especially when the clinical trial involves a vulnerable population, and only Brazil and Argentina question the study design' (Ibid., p.66). In this vein, the protocol of the iPrEx trial recommended that 'in cases of low levels of literacy, we will read the informed consent, and/or approved supporting material aloud, as well as make it available in written form to the

participant' (iPrEX protocol 2012:82).[24] This recommendation is troublesome, particularly when comparing the results of the PROUD trial with the iPrEX trial. It would be an error to suggest that lack of formal education/literacy equates with less capacity to understand how a clinical trial works. However, it has been demonstrated that formal education is a social determinant of health. Again, this is not because people with lower levels of formal education are not able to understand health-related information, but because they often cannot access the kind of information which will enable them to take decisions or navigate health care systems.

The existing literacy breach between the PROUD trial and the iPrEX study allows for further considerations. Thus, from a prefigurative biopolitics point of view, as important as it is to deliver proper information about the trial to the participants, it is also important to create the necessary conditions that will ensure that participants agree to take part in it for the right reasons. These conditions might include incorporating participants in the decision-making process of the trial, thereby securing a non-vertical distribution of power. In terms of prefigurative politics it also means having in mind the concept of solidarity when recruiting participants that belong to marginalised populations. This solidarity needs to be understood not in terms of charity, but in terms of addressing those structural conditions that marginalise the targeted population. Then, if literacy in general is a problem, clinical trial within such a population should be reconsidered. If it is true that the goal of a clinical trial is to prove the efficacy of a drug and not to attempt a reform of the living conditions of the recruited participants, it is also true that participating in a clinical trial should never have the effect of worsening or putting at risk the lives of those who participate in it. Some of these proposals were already implemented in the PROUD trial in England.

[24]https://www.nejm.org/doi/suppl/10.1056/NEJMoa1011205/suppl_file/nejmoa1011205_appendix.pdf

I asked one of the participants who took part in the PROUD trial about this feeling regarding the dynamics of power:

> Q. When you were doing this study, you know, this experience of being the object of a study or a subject of a study, did you feel more like you were being an object or a subject of study? You know what I mean?
>
> A. Yes, you know, the experience depended on who I saw when I went back into the clinic. Some of the clinicians I saw, I didn't feel like that. I felt like it was about me, and for others, it was around a little bit of a tick box exercise, "Can you fill this and do this. You got to this now and file that." It was then a little bit like, "You're doing this, that's your choice and we're observing and kind of looking in on that and so we need these things from you." Whereas the other experiences, it felt like that person who was sat next to me was actually beside me and was interested in my life in a way, you know, "What's going on, what's this, what's that?" Yes, I think that made a difference really, who I saw going through the study. (Leo. Age 40. East London)

This testimony provides an insight into the subjective experience of what it meant to be a PROUD clinical trial participant. There is a moment in which the participant feels somewhat alienated when he is required to do certain paperwork. It is in these moments that he appeals to his own commitment to the clinical trial and those uncomfortable feelings seem to be a part of the clinical trial. From a prefigurative biopolitics standpoint, the question would be how to make the participant in the trial understand that collecting that information is part of a transformative experience. In this sense, he makes clear that he also experienced a more positive relationship with the other clinicians who seemed interested in him as a person and not merely an object of a study. Prefigurative biopolitics puts the stress on the latter relationships and puts the people participating in the trial at the centre of the study. Moreover, it is a question of how to make the people running the trials understand that their roles are not to play the experts and treat the participants like objects, but to see themselves as equal partners in an exchange in which they have some expertise but the participants have other

expertise/experiences which are necessary for the success of the trial itself, basically, breaking down the expert/participant hierarchy.

The IMPACT trial is the last trial implemented using Truvada for PrEP in England. It represents an example of how it is possible to provide free access to antiretroviral medication for prevention to thousands of gay men while monitoring the use and health of those who participate in the trial. It is not a trial in the traditional sense, since the goal of the trial is not to determine the efficacy of Truvada or how safe the drug is. The trial was a further step in the implementation of PrEP in England. The participant information and consent sheet for the trial states that the trial aims to answer three questions: '1.How many people attending sexual health clinics need PrEP? 2.How many of these start PrEP? 3.How long do they need PrEP for?' [25] Participants in this study who were in this trial commented positively about it. I asked one person who was considering being part of the trial what were his reasons for taking part:

> I feel like I'm interested. I've never been in a clinical trial before. I'm interested in that process. I also feel like if I can get it for free, then I'd rather do that than this. Again, I've used a few different companies now and the process is-- getting maybe, I know I've done it I think three times. I feel a little more reassured about the whole, "This is a weird looking website," and putting my credit card details in but there's still that kind of feeling that there is something slightly-- Yes, what's the word? Improvised? Not exactly improvised but this isn't the smooth-- It's not corporate branding like I'm used to seeing on the pharmaceutical sites. It's not like buying things from Amazon where you've got that reassurance that "Okay, these things are coming." It's a? little, "Yes, we've received your order. You might get it in six weeks but we're really busy." Whenever it arrives, I'm like "Okay." Yes, so I kind of feel if I can get it for free, that would be great and also that having had these, "I've forgotten to take the last one or it's delayed or I? have run out," that actually, maybe moving on to daily wouldn't be such a bad idea. If I'm not paying for it for

[25] https://www.prepimpacttrial.org.uk/about-prep

myself, then I'd feel less bad about taking a pill every day, even if I don't need it, so yes. (Liam. Age 39. London).

Although PrEP activists are advocating for free PrEP to all those who want it, I believe that this option is, until the general rollout, an appropriate approach from a public health perspective, since it has been pointed out that some of those who buy PrEP online are not following the medical protocol.

In conclusion, the substantial differences between the two trials point to a different treatment of the people involved. Obviously, the design of the PROUD trial protocol as well as the fact that once the adherence of participants proved the effectiveness of the intervention, the referral group was administered Truvada, hints to the success of the trial in following ethical guidelines. However, it is absolutely necessary to make clear that such success is supported on results from the iPrEx study, which was far from being exemplary. This means that, although England makes clear that is a leading country in HIV prevention, this is not without ethical questions.

Health commodity activism within prefigurative biopolitics

Data published recently by Public Health England has revealed that some populations are not benefiting from PrEP as much as white gay men are (*HIV, The Lancet* March 2020). Although PrEP activists have engaged in health promotion activities, including peer education interventions for groups that traditionally have had less access to education and information about HIV prevention interventions, a market-based approach to HIV prevention is problematic for several reasons. Firstly, this approach represents the privatisation of health services by selling antiretroviral drugs at prices that not everyone can afford. Moreover, the technological way in which the sales are done is not accessible for everyone. This is clearly not an egalitarian approach to health distribution. In this sense, some of the interviewees who participated in this

project acknowledged that having to buy PrEP was sometimes difficult to afford or was just complicated. The following testimonies are part of the conversation with two of the participants regarding the available sources to get PrEP:

> Q. Well, they, IwantPrEPnow, and also clinicians recommend Dynamix International instead of other ones. Why? I don't know why.
> A. And they were nightmare Dynamix. I mean when I started off, I used them once and then I used Green Cross, is it Green Cross, Green Pharmacy, because Dynamix used to ... it was all this kind of slightly nightmarish thing about trying to find out what's your code and whether if had it been sent and it just, I think it was amateur field, I think it was people running it out of the goodness of their heart ....and it blossomed and they got no....I think the IMPACT trial is taking a lot of the pressure off them, cause it removed a great deal of the UK market or whatever. And I know there are all sorts of problems (William. Age 58 Brighton).

> Q. And how do you get PrEP?
> A. I order from Greencross pharmacy, I think it's called, online. And it's quite good.
> Q. And how much it costs?
> A. It's in dollars I think, we always buy 6 bottles. I think it's 160 dollars, maybe? So, we did order from somewhere else before, but it was more expensive. But, I'm not sure how much it was, cause the last bunch my partner ordered, and I ordered a few months ago, so I'm not quite sure. But it's not what the clinic would recommend you. It is not the link they give you to order that stuff, but it's safe as well.
> Q. Well it's very interesting, cause seemingly everybody is taking it from IwantPrEPnow.
> A. Yes, that's where they told me to get from, but it is more expensive. (Christian. Age 31. Brighton)

The first participant perceived the process of buying PrEP online through that specific online pharmacy as a complicated and troubling process. The second participant's testimony provides

information about how clinicians were initially recommending one pharmacy online, but then users would research other options. This supports the argument of the commodification of PrEP argument in chapter three. It also points to the concerns that gay men had in regard to buying PrEP.

The second aspect that problematises the act of buying antiretroviral drugs online is that the relationship between producers/sellers is one of competition. Big pharmaceutical companies are therefore more likely to shape the HIV prevention agenda in terms of policy making as well as influencing the way in which that gay men are talking about HIV prevention. As an illustration of this, in June 2019 Gilead Sciences, the company that owns the patent for Truvada, announced their financial support for the Gay Men of Color Fellowships in Biomedical HIV prevention with the goal of increasing literacy around biomedical HIV prevention and policy (NMAC 2019). Although this grant is based in the United States it is clear from the testimonies of the participants that there is a flux of information that comes from the United States shaping opinions and attitudes towards biomedical HIV prevention in England.

Finally, a market-based approach tends to transfer to gay men the whole responsibility over their health without acknowledging the different social and structural conditionings. Aware of the limitations of this model, PrEPster activist Will Nutland stated to the media that 'Buying PrEP online is a short-term solution. It creates health inequalities and will not work in the long run' (*The Independent* 2018). However, it is important to note that commodity activism can be understood as a necessary response to barriers in access to clinical trials. Thus, some men in this study have commented that certain criteria to get access to the trial acted as a barrier. In this sense, some gay men found it difficult that they had to acknowledge the real possibility of having unprotected sex in the near future since this implied recognizing the moral category of irresponsible citizenship.

Conclusion

This chapter has put the focus on those aspects in the PrEP implementation process in England that can be analysed as a case for pre-figurative biopolitics. As explained in the introduction to the chapter, prefigurative politics can be defined as those practices that aim to mirror what a better imagined future could bring into the present. It is a matter of ethically criticizing or pointing to what is wrong in society, and also a constructive approach to a problematic situation. Thus, I have argued that prefigurative biopolitics need to be understood as the politics of life itself that envision positive transformative consequences not only for oneself but also for society. Overall, it has been shown that the success of biomedical methods of HIV prevention intervention varies greatly according to the different human geographies where it is applied.

This chapter began by stating that PrEP has been characterised as a game changer within the end of AIDS narrative, which is highly problematic since it creates a false illusion that the epidemic can end simply because of another tool in the prevention kit. I argue that, from a prefigurative biopolitics perspective, it is necessary to remove the barriers that prevent access to PrEP, but also to examine how cultural and social factors play a role in the implementation of PrEP. Also, the life-long medicalisation of gay men who are not HIV-positive with the aim of finishing an epidemic is questionable.

This chapter has also put a good deal of focus on clinical trials, exposing the different results of the trials depending on the geographic region in which they have been carried out. Although the PROUD trial in England was designed in an almost perfect ethical way, it is necessary to highlight that the success of biomedical interventions rely on access to technoscientific knowledge. In England, the IMPACT clinical trial has been able to provide and monitor the use of PrEP in thousands of men. However, some participants considered that the criteria for taking part in the trial were a barrier to accessing it. Finally, commodity

activism, despite the limitations it presents for universal access to antiretroviral drugs, has been a solution for those who found barriers to accessing clinical trials.

Chapter 8: Conclusion

This thesis began as an attempt to answer an apparently simple question: why do gay men, whose bodies do not live with HIV, decide to engage in an antiretroviral regimen? When I first posed this question, PrEP was a highly controversial topic. Four years later, in 2020, the value of PrEP as a strategy for HIV prevention has been amply demonstrated, yet the legitimacy of this research question remains as timely as ever. Its value lies in understanding the historical, sociological and personal factors that have made it possible for gay men in England to be both the subjects and objects of a biomedical intervention. Questions about power relationships between HIV assemblages and gay men arose immediately, and in turn the question of personal agency emerged. In practice, no-one forced these men to take these medicines, although theories of pharmacological and social control suggest otherwise. To confront these theories, it became necessary to ask these men about their reasons for taking PrEP. Primary data from these interviews was analysed along with other primary and secondary sources. The following section provides an overview of the empirical and theoretical contributions of this thesis.

Empirical and theoretical contributions

In general terms, and as a vehicle to answer the main research question, this thesis has focused on analysing the processes of implementation of PrEP in England. Chronologically, this biomedical intervention began in 2013, with the PROUD trial, and finished on July 2020 when the British government gave the green light to local authorities to commission PrEP after the results of two clinical trials. For the analysis of this biomedical intervention, I have focused both on the historical/social aspects characterised by the presence of HIV prevention assemblages, and on aspects that directly concerned the individuals who were the objects and subjects of the said biomedical intervention. As a consequence of these two dimensions of the intervention – the macro medico-social/public and the micro dimensions – the analysis of this

intervention has required a multidisciplinary approach. The macro-level analysis of this thesis required a markedly historiographical approach that was complemented by sociological perspectives on medicine and HIV prevention. The micro-level analysis was strongly shaped by Foucauldian scholarship, especially those aspects related to the production of PrEP-related subjectivities and the governmental aspect of the intervention. However, due to the intimate relationship that the personal has with the public, the two aspects were often analysed together throughout this work. In what follows, I will review the social historical aspects of the implementation of PrEP in England that this work has emphasised.

One of the endeavours of this thesis has been to illustrate how sex between men has been continuously medicalised since the nineteenth century and how that medicalisation of sex reached its peak with the appearance of PrEP practices in England. But, most importantly, I have illustrated the evolving relationship that gay men have had with medical apparatuses. After the efforts to end the pathologisation of homosexuality as a mental illness by the gay liberation movement in England, it was considered that both the treatment and prevention of HIV/AIDS were fundamental loci for the medicalisation of sex between men. This thesis has proved that PrEP, as a biomedical intervention, clearly intensifies the influence of medicine in PrEP users' lives. This medicalisation of sex lives will probably increase in the short term since the rise of condomless sex that PrEP might bring can contribute to the proliferation of sexual infections, 'threatening the overall sexual health of the population' (The Lancet 2020). This will pose new challenges for Public Health England, and it will be necessary to remain alert to the new forms of biomedical interventions that will address these new challenges. As I have illustrated in the thesis, although the term medicalisation has traditionally been used as a form of social critique of medicine, new forms of relationship between medicine and its targeted populations have emerged.

In this thesis I have mostly used the term biomedicalisation (Clark et al. 2013) to refer to the ways in which the technoscientific advances of the last four decades have intensified the role of medicine in the lives of gay men. Within this sociological perspective, and as a strong contribution to the biomedicalisation scholarship, this thesis has shown how the implementation of PrEP in England fits and challenges biomedicalisation processes, including the commodification of health, the development of theories of risk and the production of new technoscientific subjectivities. An example of this is how PrEP in England has contributed to varying degrees to the commodification of sexual health. Although initially activists created grey markets on the Internet to access PrEP, this was perceived by PrEP users to be a lesser evil, and, ultimately, it was a necessary part of the implementation process of PrEP in England. As I have explained in the thesis, the commodification of PrEP in England was favoured by a historical reconfiguration of gay male patients as sexual health users/consumers. This reconfiguration has been part of a broader historical process, which is the continuous trend towards the privatisation of public health services characterised by, paradoxically, a high level of regulatory policies. These regulatory policies were in part responsible for the delay of the implementation of PrEP in England. Regardless of the positive outcome of this commodification, I believe that strategies like this one should not be encouraged since it sets a strong precedent in terms of handing over government responsibility to individuals.

Within the medico-social processes that have enabled the processes of PrEP implementation in England, I have paid special attention to what I have defined as the PrEP response that was led in England by PrEP activism. I have also argued that PrEP activism emerged from the confluence of three public health models – single-issue, environmentalist and pharmaceutical – that have coexisted in England as a response to particular challenges in the management of the health of the population. These types of public health engender a different type of medical subjectivity as does PrEP activism. The role of PrEP activism is

central to this thesis and it has to be understood in terms of an assemblage of different statutory and non-statutory actors. One key aspect of PrEP activism is that, as a response to the lack of provision of PrEP by the government, it adopted old practices of AIDS activism, such as the creation of grey markets, combined with new marketing strategies on the internet. A clear conclusion of this section of the thesis is that the demand for PrEP was an 'artificial' demand created by a public health challenge. There were no gay men, outside the assemblage of PrEP activism, asking for chemical prophylaxis prior to the implementation of clinical trials.

The individual dimension and the concept of antiretroviral gay body as contribution to knowledge

I have developed the concept of 'non-positive antiretroviral gay body' to produce and answer questions about the relationship between non-positive gay men and HIV prevention actors and methods. As I explained in the introduction and the methodological chapters, gay bodies are sites both for intervention and resistance, and sites in which socio-medical discourses are articulated. I have also used this concept to reflect on pharmaco-sexual subjectivities and the ways in which antiretroviral drugs access is shaping new forms of pharmaceutical citizenships. In this sense, the concept of the non-positive antiretroviral gay body is a clear contribution to the 'body studies' field, which has expanded markedly since the 1970s.

Regarding the analysis of the individual dimensions of PrEP practices in England, which are inexorably intertwined with the macrosocial, I scrutinised the concept of the PrEP subject as a neoliberal sexual actor. In order to do that, I outlined the history of neoliberalism, differentiating it from classical liberalism to understand the similarities and differences between a liberal actor and a neoliberal actor. Neoliberalism is not a monolithic concept and, as an economical and governmental doctrine, it has been adapted to varying degrees in different parts of the world. Another important point for the analysis of the neoliberal sexual actor is that the term neoliberal is loaded with moral meaning. In this sense, a neoliberal subject is

understood as a competing subject that holds others responsible for their decision-making abilities. The concept of personal responsibility, which has been widely adopted by English neoliberal policies regarding HIV health and prevention, is the subject of my research, which concluded that responsibility is understood in very different ways by gay men. Thus, the concept of responsibility is understood not only as a form of gay governmentality, but also as an act of solidarity towards the other and towards the community. Caring for oneself is understood as caring for the other and caring for the community. Finally, my work shows how the use of the neoliberal sexual actor metaphor is inappropriate and counterproductive to describe the PrEP user in England for the following reasons. As an academic contribution to sexuality studies, I have argued that i) the negative moral burden of the term neoliberal disempowers people who participate in studies on sexuality, and ii) the "neoliberal sexual actor" should be analysed in relation to the country's neoliberal policies in which the study is developed and not solely based on the testimonies of people whose decision-making is more complex than the characterisation of the neoliberal subject (that is, rational actor, responsibilisation, entrepreneur of the self).

Another aspect that has been investigated in depth is the relationship between what I have defined as ‘freedom practices’ and government practices, within the particular context of a biomedical intervention such as PrEP. This section of the thesis contrasted the testimonies of the participants with theories of social and molecular control. In this sense, the participants pointed out that the use of PrEP, contrary to theories of molecular servility, played a necessary role in terms of risk control in sexual settings. This takeover, in which risk is minimised through PrEP, was perceived as a liberating practice. However, it must be said that as a consequence of the use of PrEP, there has been a reconfiguration of sexual scenarios; participants tended to choose people who were taking antiretrovirals for treatment or prevention. This has the potential to create social pressure for gay men who do not take PrEP. It is in this space that

resistance to gay governmentality occurs. However, and as pointed out in that chapter, the government of sexuality within HIV prevention should not be understood as something intrinsically negative, since to be governed does not necessarily mean to be oppressed. In this sense, this chapter advocates softening the idea of a sharp binarism between oppressive governmentality and liberated individualism.

In the last chapter of the thesis I rely on the concept of prefigurative politics to critically analyse the success of the implementation of PrEP in England within the framework of global health. To do so I look at the role of the different PrEP clinical trials in the implementation of PrEP. Part of the contribution of this thesis to academic knowledge is the use of the concept of prefigurative politics applied to the use of antiretrovirals as HIV prevention. In addition to critically analysing a phenomenon such as the implementation of HIV prevention policies, the concept of prefigurative biopolitics allows us to think about the ways in which PrEP practices can be transformative at a structural level. In this sense, part of PrEP activism in England has been giving voice and space to minorities that have traditionally had less access to health resources.

Concluding remarks on methodology

The questions that this thesis aimed to answer required, as I said above, a multidisciplinary approach, but also a qualitative mixed-method design. For the part that investigated the social or 'macro' phenomena of the implementation of PrEP in England, I relied largely on secondary sources and archival research, but also oral history interviews. Thus, to better understand the reconfiguration that is taking place in England from patients to consumers/users of public health, it was necessary not only to delve into policy documents and the work of other historians, but also to look at testimonies from the oral history interviews and documentation from archival resources. As I explained in the methodology section, I visited several archives, but the Brighton archives The Keep, where the NLGS collection is located, and the archives of

the University of California were especially useful, both in terms of sourcing data and placing the history of HIV in England within a geographical and historical perspective. The digitisation of this type of sources represents a breakthrough for future historians of HIV / AIDS and will undoubtedly facilitate comparative studies on the history of antiretroviral drugs.

Oral history interviews were a very valuable data source, specifically for the study of the production of PrEP-related subjectivities. The interviews were analysed in relation to the two fundamental social theories that form the backbone of this thesis, biomedicalisation and the concept of governmentality and to examine, which allowed me to examine the relationship between PrEP and the governable subject. In this sense, I used the two theories as a methodology to answer questions about how gay men are both subjects and objects of biomedicalisation, and how the process of the implementation of PrEP fits within the parameters of biomedicalisation. One innovation of this project has been to prove the potential of combining theories of biomedicalisation and governmentality with oral history, since both methodologies are strongly linked to the problematisation of subjectivity.

On a personal note, I have to acknowledge that some interviews were especially delicate to carry out. As an interlocutor, I consider that it is essential to find the balance between listening carefully and showing empathy for what is being said without being carried away by emotions. On the other hand, the process of listening to the recordings and reading the transcripts in my own space gave me the opportunity to really empathise with the depth of what was sometimes being talked about. In the history of HIV and AIDS, death is a normal, everyday element. It is not uncommon to read testimonies of gay men on social media stating that they have lost dozens or even hundreds of friends. For me this was a problematic point since I consider that there is a risk of fetishizing death through numbers. More personal testimonies provided me with the opportunity to understand/empathise with the dimensions of the tragedy.

For example, when a participant mentioned that he lived in the same apartment where one of his partners had died, it was easier for me to imagine the trauma he had gone through.

The future of PrEP and other biomedical interventions

The future of HIV prevention seems to be heading for evolving biomedical approaches. Efforts are already being directed to producing new forms of PrEP consisting of new combinations of antiretrovirals with fewer side effects and new ways of administration to help users with adherence issues. These new forms of administration feature injectables that can release long-acting antiretrovirals, implants and vaginal rings that release antiretrovirals into the body over time and antibodies infused into the body. These are all forms of PrEP that are under current experimentation, but it seems clear that the biomedicalised ways of preventing PrEP will dominate the future landscape of HIV prevention. This can benefit populations in various ways, for example with adherence issues, or the necessity of being discreet taking PrEP. Nevertheless, the intimate relationship of the PrEP users with medicine will still be there.

The commitment to the biomedicalisation of HIV prevention nowadays involves the development of health technologies in increasingly commodified markets of health provision. This will enable new forms of power relationships between the subjects of biomedical interventions and medicine itself. However, this setting must take into account the fact that biomedicalisation will benefit certain populations to the detriment of others if structural barriers are not taken into consideration. There is a historic opportunity for medicine and biomedical interventions to transform not only individuals, but also societies. However, their success will depend on the democratisation of resources and the will to address inequalities and barriers to health with the same determination that has been present in producing new biomedical forms of care.

New forms of biomedical interventions, not only for HIV prevention and treatment, constitute a fascinating area of study for the medical humanities field. Interventions on bodies

will always reflect the nature of power at a certain historical time and therefore provide us with the opportunity to better understand who we are as humans. The governmental aspects of biomedical and also behavioural interventions, as is happening today with the COVID 19 pandemic, will also provide innumerable opportunities to reflect on human fears, emotions, aspirations and desires. How these interventions are embraced in different contexts and how theories of biomedicalisation and governmentality travel around the globe will require specific lenses. It is my desire to keep making contributions to this field of the medical humanities and I hope to keep using oral history as a vehicle to not only obtain data, but also to keep a record of the voices of the history of the present, which often fade away without the recognition they deserve.

Appendix one. Ethical approval and sample Consent Form

The research for this project was submitted for ethics considerations under the reference HUM 17/021 in the Department of Humanities and was approved under the procedures of the University of Roehampton's Ethics Committee on 21/03/2017

University of Roehampton London

Title of Research Project:

The Antiretroviral Gay Body: The Production of Subjectivities in HIV Treatment and Prevention in the UK

Brief Description of Research Project, and What Participation Involves:

This project is a study about the role of antiretroviral drugs in shaping the lived experiences of gay population in UK. Thirty recorded interviews (duration 2 hours) conducted with men who have used antiretroviral drugs for means of HIV treatment or prevention will complement my literary research. I chose this theme as I am fascinated with the historic relationship between the pharmacology industry and the governance of gay population. This academic research relates to my own doctoral degree and my previous interest in HIV issues. The only people who will read your testimonies are University Professors and administration staff in the UK within their role of assessing my work. In any publications resulting from this research (for example, academic articles or books) excerpts from your interview will appear under a fictions name and any details that may identify you changes, in order to guard your anonymity. (unless you decide to keep your identity)

Investigator Contact Details:

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Consent Statement:

I agree to take part in this research, and I am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

Name …….

Signature ……

Date ……

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies.) However, if you would like to contact an independent party please contact the Head of Department.

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Contributor 325's response to the Gay men and health Directive RefNo: SxMOA16/1/2/26/2 (barcode: 0022686)

Contributor 367's response to the Gay men and health Directive RefNo: SxMOA16/1/3/12/2 (barcode: 0022687)

Copies of Directives sent out to series 2 respondents Ref No: SxMOA16/2/1/2, Alt Ref No: 7/2 (barcode: 0022690)

Copies of Directives sent out to series 1 respondents Ref No: SxMOA16/2/1/1, Alt Ref No: 7/1 (barcode: 0022690)

Contributor 307's response to the Gay men and health Directive Ref No: SxMOA16/1/2/16/2 (barcode: 0022686)

Contributor 212's response to the 'Gay men and health" Directive Ref No: SxMOA16/1/2/2/2 (barcode: 0022684)

Contributor 274's response to the 'Early perceptions of homosexuality' Directive Ref No: SxMOA16/1/1/75/1 (barcode: 0022685)

Contributor 307's response to the Gay men and health Directive Ref No: SxMOA16/1/2/16/2 (barcode: 0022686)

Contributor 220's response to the Gay men and health Directive Ref No: SxMOA16/1/1/51/2 (barcode: 0022685)

Contributor 161's response to the Gay men and the police Directive Ref No: SxMOA16/1/1/26/2 (barcode: 0022684)

Contributor 301's response to the Gay men and health Directive Ref No: SxMOA16/1/2/13/2 (barcode: 0022686)

Contributor 294's response to the 'Gay men and health" Directive Ref No: SxMOA16/1/2/12/3 (barcode: 0022684)

Contributor 283's response to the 'Gay men and health" Directive Ref No: SxMOA16/1/2/9/3 (barcode: 0022684)

Contributor 212's response to the 'Gay men and health" Directive Ref No: SxMOA16/1/2/2/2 (barcode: 0022684)

Mass Observer S473RefNo: SxMOA2/1/21/2/2/496 (barcode: 0217581)

AIDS collection at the Archives & Special Collections, UCSF Library & CK

Box 1, Folder 1 Description and History undated

Box 1, Folder 2 Articles & Bylaws undated

Box 1, Folder 3 Board of Directors: Lists, Correspondence undated

Box 1, Folder 4 Board Minutes 1987-1988

Box 1, Folder 5 Board Minutes 1989-1990

Box 1, Folder 6 Board Minutes 1991-1992

Box 1, Folder 7 Board Minutes 1993-1994

Box 1, Folder 8 Operations Committee 1991-1992

Box 1, Folder 9 Staff: Policies, Procedures, Memos, etc undated

Box 1, Folder 10 Board & Staff Retreat 1993

Box 1, Folder 21 National Buyers Club undated

Box 1, Folder 22 Passive Immunotherapy Foundation; Correspondence 1989-1994

Box 1, Folder 23 Local Independent Agencies and Combined Charities undated

Box 1, Folder 24 FDA and 1992 ddC Incident 1992

Box 1, Folder 24 FDA and 1992 ddC Incident 1992

Box 1, Folder 25 Ordering, Product Notes, Price List undated

Box 1, Folder 26 Inventory, March 1992

Guerrilla Clinic Records, MSS 90-13,

Oral history interviews

Pseudonym applied to the following interviewees

Greg Owen. Age 36. London	02/06/2017
Doctor Evans . Age 83. Central London.	15/07/2017
Sean . Age 39. Leeds. (PrEP user)	29/07/2017
Koldo . Age 51. Hackney.	03/08/2017
Ron. Age 36. Central London. (PrEP user)	03/08/2017
Percy. Age 48. West London	15/08/2017
Mike. Age 50. Central London.	15/08/2017
Logan. Age 49. East London (PrEP user)	24/07/2017
Liam. Age 39. East London (PrEP user)	13/09/2017
Leo. Age 40. East London (PrEP user)	16/09/2017
Carlo Age 39. East Croydon (PrEP user)	10/10/2017
Jad George. Age 58. North London.	16/10/2017
William. Age 58. Brighton (PrEP user)	04/09/2018
Edward. Age 38. Brighton (PrEP user)	17/10/2017
Harvey. Age. 63 West London.	26/11/2017

Daniel. Age 49. Lichfield (PrEP user)	24/01/2018
Warren. Age 54. Southeast London (PrEP user)	25/01/2018
Christian. Age 31. Brighton (PrEP user)	27/01/2018
Saul . Age 27. West London (PrEP user)	11/02/2018
Jim. Age 34. Brighton. (PrEP user)	14/02/2018
Errol. Age 30. Brighton (PrEP user)	20/02/2018
Andy. Age 27. North London (PrEP user)	26/09/2018
Jeremy. Age 70. Deal	22/05/2018

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